Effective Mental Health Service User Involvement

Establishing a consensus on indicators of effective involvement in mental health services

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CONTENTS

ABSTRACT

Mental health service user involvement had been UK government policy since the early 1990s. This dissertation explored the current state of policy and practice in mental health service user involvement by reviewing peer reviewed literature. A number of potential indicators of effective involvement were drawn from the literature. A discrepancy was found between policy and practice and the concept of indicators of effective involvement was proposed to support the process of enabling practice to develop to match policy expectations.

A number of approaches to developing indicators were explored, with the explicit aim of introducing greater mental health service user ownership of the concept of effective involvement. In order to ensure both broad engagement and a degree of consensus, the Delphi process was chosen.

An expert panel of mental health service users from England was recruited against a person specification co-developed with the National Survivor User Network (NSUN, an England wide, national network led by and for mental health service users). The 38 panel members represented a spread of ages and came from every region of the country. They have experience of and expertise in involvement at a strategic, operational and individual level. The panel completed two rounds of a Delphi process using an online tool.

The panel reached consensus on 21 indicators of effective mental health service user involvement. There was a clear preference for collaborative involvement where service users and professionals worked together in a partnership that was as equal as possible.

The chosen indicators have already influenced a number of international, national and local initiatives and have been used to support the development national standards for service user involvement in England.

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1 INTRODUCTION

1.1 CONTEXT

Mental health services have evolved from institutionalised care delivered in large hospitals to individualised care and treatment packages that are mostly based in community settings. Most people using mental health services are now living in their own homes or other community settings. People with a psychiatric diagnosis should no longer be passive recipients of treatment dispensed by professionals, but active partners in their own care.

1.1.1 Policy Context

UK mental health policy now treats service user involvement as both a right and a reasonable expectation. A more detailed analysis of relevant policies can be found in chapter 2.

1.2 SERVICE USER NETWORKS IN THE UK

The UK has had national mental health service user networks since the formation of Survivors Speak Out in 1986. The National Survivor User Network (NSUN) is an independent service user led national network of individuals and service user groups from across England. NSUN has been leading mental health service user involvement at a national level in England since 2007. In 2012, as an initiative to improve the theory and practice of service user involvement, NSUN developed its National Involvement Partnership, bringing together a range of experts in mental health service user involvement.

The National Involvement Partnership (NIP) project 'Involvement for Influence – Influence for Improvement' aims to develop national standards for the involvement of service users and carers in mental health and social care services, and establish a national infrastructure for involvement. The aim is to 'hard wire' the service user and carer voice and experience into the planning, delivery and evaluation of health and care services. The project aims to share good practice, centralise resources, strengthen existing networks and build an infrastructure that connects and coordinates involvement. It will promote user and carer leadership, realising the vision "nothing about us without us".

The work of the National Involvement Partnership is led by NSUN and includes a number of other organisations: the Afiya Trust, a voluntary sector organisation run by and for people from minority ethnic communities; the Social Perspectives Network (SPN), a network of social care professionals, policy makers, service users and carers; and the Mental Health Foundation, a mental health research and development organisation (my employer, described below). This three year programme of work is funded by the Department of Health, and aims to bring together all of the knowledge and expertise about service user and carer involvement, built up over the last few decades, in one place.

1.3 THE MENTAL HEALTH FOUNDATION

The Mental Health Foundation is a UK based voluntary sector organisation. The Foundation engages in research and development with a particular emphasis on applied social research and has funded, developed, supported and researched service user led initiatives for over 25 years. The Foundation jointly funded the development of NSUN and has supported the development of similar networks in Scotland and Wales.

More recently, the Foundation has started to develop tools and techniques to allow mental health service users to take more control of their own conditions, lives and become actively involved in service development and delivery; often working in partnership with local or national organisations.

1.4 MY EXPERIENCE

The importance I place on mental health service user involvement is a result of my personal experience. I first used mental health services at the age of 14 in the late 1970s. I continued to spend time in psychiatric hospitals over the following 15 years and received 6 different diagnoses and completed two admissions as a detained patient. Throughout this period I was studying and working. My professional background was as an economist and statistician and I was frequently struck and confused by the different way I was treated by people depending on context.

It became clear to me that the role of mental health service user was primarily a passive one in which things were done *for* and *to* me rather *by* or *with* me. In the late 1980s I became a member of, and then actively involved in Survivors Speak Out, the national service user led organisation of the time. One of the underpinning principles of the organisation was that people should have the primary voice in their own care and treatment, and that this state was best achieved collectively and through people supporting each other. This experience formed the basis of my interest in mental health service user involvement.

1.5 THIS DISSERTATION

As I became more engaged in service user involvement, and as public services became more consumer orientated, the concept of effective involvement became more important to me. This dissertation documents my contribution to the process of understanding what makes mental health service user involvement effective. A summary of the structure follows.

1.5.1 Terms of reference/objectives and literature Review

The dissertation starts with a review of the state of service user involvement, both in policy and practice, examines the evidence base for different approaches to involvement. It includes a brief explanation of the style and some of the key language used, including cultural variations in language. It then explores a number of studies in more detail to extract some of the elements of involvement that have potential to become indicators of effectiveness.

1.5.2 Research design and methodology

This section of the dissertation explains my approach to exploring effective mental health service user involvement, including the underpinning importance of power relationships, both on the research paradigm and the nature of mental health services. I then compare some potential research methods and explain my choice. This includes a discussion of the concept of consensus and how I have chosen to interpret and apply it to this research.

1.5.3 Research activity

This section of the dissertation describes the research in detail, including how I defined the questions for the Delphi process, determined the panel size, recruited the panel members, tested the software used, conducted the Delphi research, and analysed the data it produced. The Delphi panel members' experience is described in detail.

1.5.4 Findings

This section of the dissertation describes the results of the Delphi research. This includes the consensus reached during the first round, changes made between rounds and the results of the second round. It also includes a brief review of the comments made by panel members.

1.5.5 Discussion

This section of the dissertation presents an interpretation of the findings. It places them in the context of the current state of policy, legislative and service provision in the mental health field. There is a discussion on the limitation of the current state of the literature on mental health service user involvement. The chapter includes an interpretation of the findings of the Delphi research and the comments made by panel members throughout the process.

1.5.6 Conclusion and recommendations

This section of the dissertation presents the impact of the work to date, expected impact in the shorter term, and recommendations for longer term development.

2 TERMS OF REFERENCE AND LITERATURE REVIEW

2.1 INTRODUCTION

This chapter outlines the purpose of my research, some of the important terms used and the broader context around mental health service user involvement, reviews the current state of literature and draws on existing research to identify potential indicators of effective involvement. It will also identify where this work sits as part of a broader piece of work on developing national standards for mental health service user involvement for England.

2.2 AIMS

The aim of this research is to improve the effectiveness of mental health service user involvement in mental health services. In order to achieve this aim, I have set the following objectives: identify potential indicators of effective mental health services user involvement from existing research; recruit a team of service users with expertise in involvement; facilitate a process by which the experts agree indicators of effective involvement; support the use of the indicators as a way to improve effective involvement.

2.3 A NOTE ON STYLE, LANGUAGE AND TERMS USED

I have written this dissertation in the first person. Although this is not the traditional academic style, I have used it to emphasise the personal nature of this work and to build on the narrative tradition that has become an important part of the service user involvement movement. The story of service user involvement described throughout this dissertation mirrors the journey made by many people who have used mental health services, including my own, and my choice of first person reflects this.

A number of different words and phrases are used throughout this dissertation to describe similar (or sometimes the same) concepts. There is no consensus on the best words or phrases used to describe people, services, experiences or even involvement itself. Geography, culture, professional or academic background, political persuasion and even fashion has an impact on the language used.

Where published work is being quoted or analysed, the language originally used is retained. Below is a brief guide to some of the most common terms used and how they relate to each other. A number of glossaries exist but they tend to date quickly, particularly when referring to policies or services.

2.3.1 The people

The following words and phrases are commonly used to describe people who have used mental health services: mental health service user, service user, consumer, patient, expert patient, expert by experience, person with a psychiatric diagnosis, survivor. Most of these terms could be used interchangeably although patient usually refers to some receiving care or treatment in a hospital setting; I have chosen to use mental health service user throughout as this is the term most commonly used to prefix involvement.

2.3.2 The experience/condition

While there is a degree of diversity (and certainly no consensus) around how people are described, or describe themselves, it probably constitutes something of a continuum that people place themselves (or are placed on) and although it is not uncontroversial, there seems to be a degree of acceptance of self-definition and interchangeability of terms. The phrases used to describe what

people experience, however, appear much more polarised and divisive. This polarisation is not specific to involvement, but it is often highlighted by it.

The main division is centred on whether people are defined by a medical or social construction of their experience. On the medical side the key terms used are mentally ill, severe mental illness, particular diagnoses (for example schizophrenia, bipolar disorder, depression), or symptoms (hallucinations, delusions). On the social side would be mental distress, hearing voices and other non-clinical descriptions based on people's lives rather than a perceived illness (there is also a degree of reclaiming language, following similar trends in race and sexuality where people are describing themselves and their experience as, for example mad, crazy or nutters with attitude – but this does not yet feature in the literature).

2.3.3 Involvement

In addition to the word involvement; participation, empowerment, engagement, stakeholder involvement and patient and public involvement (usually abbreviated to PPI) and co-production have been used widely. There may be different philosophies or emphases implied by the choice of term, but they generally refer to involving individuals or groups with an organisation or its activities.

2.3.4 Other terms used

There are a number of terms that relate to specific ways of delivering mental health services; these tend to be country (and often politically) specific but are associated with giving mental health service users a greater degree of involvement in either the service as a whole, or what they receive from it. These are sometimes models of care or service delivery. Examples include: personalisation, where (usually social care) services are commissioned by an individual following a detailed assessment of their needs leading to a personal budget, a pot of money given to an individual to enable them to meet their social care needs (Larsen et al., 2013); self-directed support, the process of individuals controlling their own support, either through their personal budget or some other mechanism; peer support refers to approaches based on mutual support between mental health services, though the precise nature of the peer relationship may vary from service to service; psychiatric rehabilitation and recovery, terms that refer to an individual moving towards a life less disabled by mental ill-health, in the case of recovery, this is usually at least partially defined by the service user.

2.4 POLICY CONTEXT

Service user involvement in health and social care has been UK government policy for many years. Many of the papers reviewed throughout this chapter include an overview of key legislation, often referring to the 1990 NHS and Community Care Act (DH, 1990) as the first significant piece of legislation to enshrine service user involvement in law. A paper by Basset and Evans (2009) provides a good overview of more recent legislation and policy as well as reviewing the impact of the National Service Framework for Mental Health (NSF). It includes a significant section on the impact the NSF has had on service user involvement in its first ten years.

Service user involvement remains an important part of government policy with the 2010 White Paper, Equity and Excellence: Liberating the NHS (2010) making the explicit statement "no decision about me without me", adapted from a phrase widely used in the disability movement and used in patient and public involvement in England for over 10 years (Gilbert, 2003). Table 2.1, below, sets out the Government's commitment to "putting patients and public first" taken from the executive summary of Equity and Excellence: Liberating the NHS, the current policy for England (DH, 2010).

Table 2.1 - Putting patients and public first

We will put patients at the heart of the NHS, through an information revolution and greater choice and control: a. Shared decision-making will become the norm: no decision about me without me. b. Patients will have access to the information they want, to make choices about their care. They will have increased control over their own care records. c. Patients will have choice of any provider, choice of consultant-led team, choice of GP practice and choice of treatment. We will extend choice in maternity through new maternity networks. d. The Government will enable patients to rate hospitals and clinical departments according to the quality of care they receive, and we will require hospitals to be open about mistakes and always tell patients if something has gone wrong. e. The system will focus on personalised care that reflects individuals' health and care needs, supports carers and encourages strong joint arrangements and local partnerships. f. We will strengthen the collective voice of patients and the public through arrangements led by local authorities, and at national level, through a powerful new consumer champion, HealthWatch England, located in the Care Quality Commission. g. We will seek to ensure that everyone, whatever their need or background, benefits from these arrangements.

There is a clear commitment to involvement at the individual level (points a, b, c and e), operational level (points c, d, and e) and strategic level (points e and f).

As recently as February 2014, the importance of involvement of mental health service users was reinforced by the Government's Mental Health Crisis Care Concordat (DH, 2014) which calls for "service user and carer involvement in all elements of the commissioning cycle, strategic direction, and monitoring of crisis care standards" and "clearly stated standards relating to how each service involves and informs children and young people about their care, including medication and diagnosis".

2.5 EFFECTIVE INVOLVEMENT

The purpose of this research is to identify indicators of effective involvement. Involvement is not easy to measure, but it needs to be done. An approach based on indicators offers an opportunity to establish effective involvement as an evidence based activity. Good indicators will enable mental health decision-makers, service providers and service users to ensure that the service user involvement they engage in is authentic and effective. It will help to enable people to establish that existing policy is being implemented and that resources applied to mental health service user involvement are providing a return on investment.

What is an Indicator?

For the purposes of this work, I have taken an indicator to be a descriptor of performance against agreed values or criteria. For this work, indicators will need to relate to empowerment, as defined in the work to date. In order to develop useful and usable indicators of empowerment it is important that these indicators confirm to certain characteristics; the following is adapted from work I

completed on behalf of the World Health Organisation for their work on empowerment (see WHO, 2010):

- Meaningful.
  The indicators need to measure something useful. They need to relate to core values and the definitions of empowerment that we are using. There is a risk that targets can distort practice if they are based on measuring things that do not have sufficient meaning.

- Measurable.
  To be useful, it must be possible to measure something. This measurement can take a variety of forms, for example it could be a numerical scale; a question with a simple yes or no answer; or a question with a response of the form always, usually, rarely, never. It should be possible for this measurement to be made easily without either excessive costs or disruption.

- Auditable.
  A good indicator needs to be able to be independently verifiable. Self-reporting is perfectly acceptable, provided that indicators can be audited so that they can be trusted.

- Objective.
  Indicators need to be constructed so that they do not depend on the subjective opinion of the individual who is responsible for measuring the indicators.

- Offer a scale for benchmarking/improvement indicating action for improvement.
  An effective set of indicators will need to be calibrated so that any system can identify its relative strengths. It should also enable any system to improve, no matter how good they are. A good set of indicators should make it easy to see where decision-makers need to prioritise and how they can improve.

These indicators will be drawn from evidence about what is effective in service user involvement and will be ranked and prioritised by mental health service users recruited for their experience and expertise in service user involvement.

In order to make this a manageable task, I have divided effective involvement into five questions:

1. What does involvement mean?
2. Who is involved?
3. What mechanisms exist for involvement?
4. Does involvement make a difference?
5. What are the challenges and barriers to involvement?

These questions are addressed below.

2.5.1 What does involvement mean?

The key principle of involvement is that an individual, who is experiencing mental distress to the extent where it is having a significant impact on their life, has some say in how they are treated, and that this is heard and responded to.

Throughout this research, I have divided involvement into three levels: involvement at an individual level, where people are involved in their own care; involvement at an operational level, where people are involved in the day to day running of services or organisations; and involvement at a strategic level, where people are involved in what the future looks like.

2.5.2 Who is involved?

One of the key challenges faced by service users who get actively involved is about representativeness. A number of papers refer to the issue of representativeness (see, for example, Crepaz-Keay, 1996, Valentine and Capponi, 1989), and there is a view held by some service providers that the views of actively involved service users do not accurately represent broader service user views and therefore do not carry weight or influence in planning decisions. Crawford et al. (2003) reports findings from a cross-sectional postal survey of 17 service providers and 29 service user groups in Greater London, UK. All 17 Trusts reported relationships with a number of service user groups (ranging from 3 to 11 groups per Trust). When asked about obstacles to involvement, the Trusts' concerns that the service users were not representative was the most frequent response (7 Trusts representing 44% of respondents).

Crawford and Rutter (2004) report a study which tested how well the views of service users who were actively involved represented typical service user views. The study used a cross sectional survey and received responses from 89 randomly selected patients, 8 patients who were actively involved in a local service user group, 25 service managers, 8 psychiatrists and 5 members of the local Trust board. All participants were asked to assess the priorities of 9 potential service developments or improvements. The study is careful to draw the distinction between representative in terms of accountability to a constituency of service users and representative as a proxy for the view of the wider population of service users. The study found that service user group members had very similar priorities and reflected the views of broader service users well.

Though it seems that arguments about how representative the views of active service users are seen to be an unnecessary barrier to good involvement, it remains important that involvement reflects the diversity of service users and potential service users. Whilst we know that in the UK some ethnic groups are disproportionately affected by compulsory detention (Singh et al., 2007) they appear to be under represented in service user involvement. The UK service user movement has been aware of this difficulty, exploring and restating this as a priority repeatedly throughout its history, including part of a major service user led research project from 2001-2003 (published as "On Our Own Terms", Wallcraft, 2003), a national study commissioned by the National Survivor User Network (NSUN) (Kalathil, 2008) and follow up work 3 years later (Kalathil, 2011). This work concludes that to improve broader ethnic diversity in involvement we need to both acknowledge and co-ordinate existing activity, which appears to be effective at a local level, and link this involvement to broader anti-discrimination and antiracism initiatives.

2.5.3 What mechanisms exist for involvement?

Historically, service user involvement at the operational and strategic levels has centred on attendance at meetings. However, in order to increase the diversity of people involved, a range of mechanisms is needed (Boeltzig et al., 2008, Perkins and Goddard, 2004, Rutter et al., 2004). Different people prefer to get involved in different ways and mechanisms chosen are likely to have an impact on who gets involved. A number of studies have looked beyond conventional meeting based approaches for involvement. One study with a focus on involving women in developing mental health services (Barnes et al., 2006) identified a range of different mechanisms that engaged people more effectively than conventional planning groups. The involvement centred on a single event, but service users were highly involved in the design and delivery of the day. The techniques that appeared to work well were based on story telling or narrative approaches and had a strong emotional content, with themed discussions.

Game based approaches have potential to engage people who have otherwise shown no interest in complex consultation issues (Fitzgerald et al., 2011) and Forum Theatre approaches also involve some people who have felt excluded by conventional meeting structures (McClimens and Scott, 2007).

Within meeting structures approaches like Nominal Group Technique that are designed to encourage more equal participation in meetings (Perry and Linsley, 2006, Sloan, 1999), as well as Delphi techniques that enable people to contribute their expertise and experience without having to be present at a meeting thus reducing the time commitment required and removing difficulties with the peer pressure that can occur in face to face settings (Perry and Gilbody, 2009, Langlands et al., 2008, Fiander and Burns, 2000).

2.5.4 Does involvement make a difference?

There is some evidence to support the benefits of involvement at all three levels. At an individual level, several studies found a variety of benefits accruing from self-management where people are more in control of their care and treatment including reduced admission rates, increased self-esteem and increased satisfaction (Lawn et al., 2007, Linhorst et al., 2002, Segal et al., 1993). Involvement at an operational level has shown enhanced quality of care, improved quality of life, improved relationships between staff and service users, and reduction of compulsory admissions (Thornicroft and Tansella, 2005, Peter, 2003, Minett, 2002). Evidence of the benefits of service user involvement at a strategic level was found by a systematic review of involvement in planning and development of healthcare (Crawford, 2002). The benefits included improved access to services, improved information about services and examples of completely new services. I have always believed that involvement *can* make a difference, but that it does not necessarily make a difference. One purpose of my work on effective involvement is to give people the tools to check whether existing or proposed involvement does make a difference and to focus their efforts on involvement that does.

2.5.5 What are the challenges and barriers to involvement?

A number of papers identified barriers to involvement. A study by Bowl (1996), some years after the implementation of the 1990 NHS and Community Care Act (Department of Health DH, 1990) highlighted considerable confusion about the meaning and purpose of user involvement and about how service users can best be represented. The study was based on interviews with 31 key figures in local authorities and 135 services users from across the UK. It found little evidence of power-sharing, despite users' interest and limited commitment of resources to make further participation possible. An Australian study (Happell, 2008a) interviewed 16 service users and identified themes including: staffing issues; hearing the person not the illness; lack of safety and security; and, isolation. Drawing on the same research, Happell (2008b) concluded that professionals were viewed as discriminatory and stigmatising towards mental health services users. Other studies (Stringer et al., 2008, Linhorst et al., 2002) found that care providers are still insufficiently inclined to help shape service user involvement.

Middleton et al. (2004) reviewed literature as part of a study into consumer participation in the Australian state of Victoria and identified eight barriers to involvement in mental health services: stigma and discrimination, limited involvement in development of services, the complexity of the system, agencies of social control, the position of the medical profession, representativeness and accountability, having a severe mental health problem and people using services as necessity rather than by choice.

While user involvement is frequently mentioned in policy documents, in practice the aims are not yet being fully achieved and implementation is variable. One study, from Northern Ireland (Connor and Wilson, 2006), used a grounded theory approach and purposeful sampling to conduct a detailed study of the experiences of just over 30 service users and identified language, mental health professionals, models of care, and information and communication as key challenges to making involvement effective with each theme having the potential to block progress or help support involvement when addressed well. An American study (Linhorst et al., 2002) looked specifically at treatment planning as a mechanism for participation and empowerment amongst people in a long term psychiatric hospital. Qualitative data were collected from reviewing documents, including policy documents, standards and individual patient programme materials; this was supported by 32 focus group discussions which included 72 patients and 114 staff in total. This study found that there was strong emphasis on choice and participation in the polices but much less evidence of this in patients' programmes and practice described in the focus groups. A survey of service users who were paid or unpaid workers in New South Wales, Australia (Stewart et al., 2008) found the rhetoric of 'consumer participation' did not match practice. Consumer involvement was not underpinned by relevant training and supportive infrastructure. The goal of meaningful service user involvement (referred to as consumer participation in the paper, the term most commonly used in the United States, Australia and New Zealand) in mental health services as outlined in policy is yet to be achieved in practice.

A study looking at the introduction of self-directed support in mental health services within an English Partnership Trust explored the effects of involvement on the service users and carers (Hitchen et al., 2009). This is one of the more recent papers identified and as such, it covers the UK policy position as it is currently; it highlights the fact that little has changed in terms of policies encouraging service user involvement and also that many barriers still exist. Although the policy names have changed, much of the introduction could have been written 20 years ago (see the discussion of Braye and Preston-Shoot, 1993 below, for example). The study uses participatory action research and used a research team of 12 people including three service users and two carers who were externally recruited to the team. The study identified a number of power related issues and explicitly identified language and jargon as barriers to involvement.

Training service users for involvement and clear role descriptions for people who get involved have been found to help overcome some of the barriers identified (Bailey, 2005, Middleton et al., 2004, Meehan et al., 2002).

2.6 IDENTIFYING POTENTIAL INDICATORS FROM THE LITERATURE

In order to develop a manageable framework for indicators I have adopted a three level stratification of involvement: individual, operational and strategic. The use of these levels is widely acknowledged (see, for example, Perkins and Goddard, 2004) and will also make the indicators more useful and easier to analyse and act upon in a service setting. Most of the involvement above sits at the operational level; with involvement in planning the primary reference to strategic involvement. This finding reflects my experience which suggests that people tend to conceptualise involvement primarily at an operational or strategic level, rather than a day to day part of how professionals relate to service users or about people taking more control over their lives and care. When referring to the literature I have used the terms in the original papers. The indicators chosen for the first round of the Delphi process are presented in tables at the end of each subsection, below.

2.6.1 Exclusion criteria

In order to identify potential indicators appropriate for this research I applied the following exclusion criteria, I excluded papers:

- That were not written in English. I do not speak any other languages well enough to interpret them to the standard required.
- That related to a specific intervention or therapy. The indicators need to be applicable in a range of settings, any indicators that are too specific to the intervention or the setting would be of little value.
- Where the involvement referred to groups other than service users. Many papers refer to involving professionals or other staff in services which, while important, is not relevant to this research.
- That were solely concerned with public mental health or illness prevention. These were small in number, but tended to be about involving broader populations and the techniques used were not developed with mental health service user involvement in mind.
- Papers from outside the UK where there was no potential value in a UK setting for legislative, policy, service or cultural reasons. Many papers from beyond the UK have been included, but some were too specific to particular countries to be appropriate for inclusion.
- Where there was insufficient detail in the title or abstract to assess its potential value. A number of searches returned over 100 papers. I made an initial assessment on the basis of the title or abstract to decide whether the full paper was worth reviewing.

In addition:

- I have not set a date limit on literature. Service user involvement is relatively recent and though previously identified literature reviews cite papers from 1989 (Blank et al., 2011) the majority are much more recent and limiting the date is not necessary to make the process more manageable and risks losing potentially useful information.
- A number of the papers on empowerment referred to one particular empowerment scale (Rogers et al., 1997) already identified; where this was the only relevance of the paper, I excluded it from further review.
- Except where I was specifically seeking information on indicators (see measuring involvement, below), scales or other measurement related matters, I excluded papers that did not relate predominantly to people were either using (or had used) secondary mental health services or who had a recognised psychiatric diagnosis.

2.6.2 Individual level

To seek literature on involvement in people's own care, I chose the following search terms, limiting the search to title in the first instance, I included the originally proposed general terms that I did not use in the initial search (the full list of potential indicators at an individual level, drawn from the literature, is shown in table 2.2, below).

Terms which cover the principle of involvement at an individual level:

- Empowerment
  searching on "empowerment" with the term "mental" returned 70 papers, removal of duplicates and an initial review of abstracts against my exclusion criteria left 18 papers worth further consideration.
- Participation
  searching on "participation" with the term "mental" returned 191 papers, removal of

duplicates and an initial review of abstracts against my exclusion criteria left 22 papers worth further consideration.

- Personalisation
  searching on “personalisation” with the term “mental” returned 1 paper. Extending the search to “abstract” instead of “title” returned 27 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 15 papers worth further consideration.

Terms referring to particular types of involvement at an individual level:

- Self-management
  searching on “self-management” with the term “mental” returned 20 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 9 papers worth further consideration.
- Crisis cards
  searching on “crisis card” yielded no useful results, even when searching across all fields.
- Care planning
  searching on “care plan” with the terms “involvement” and “mental” in abstracts returned 12 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 4 papers worth further consideration.
- Advanced directives
  searching on “advanced directives” with the term “mental” across all terms returned 11 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 2 papers worth further consideration.

Allowing for papers that appeared in more than one category, review of the abstracts identified a total of 61 papers which were reviewed in greater detail.

Involving people at an individual level, in their own care, is at the very core of effective involvement. It highlights every principle and every block. It reinforces the differences and discrimination faced by people with a psychiatric diagnosis.

The differences in power and status between mental health service users and professionals that underpin the paradigm and methodology of this study are at their sharpest at this level. At the heart of this level of involvement there is a transaction between two parties, but they are far from equal partners. I have started with this level because I do not believe it is possible to develop effective involvement at other levels without getting it right at this level first.

In order to be effective, mental health service user involvement needs to address the power imbalances outlined in chapter 3. Those that relate primarily to the professional, are more likely to be addressed at the operational level; this level will focus on the mental health service user or the transaction/dialogue that takes place between them and the professional.

Many of the papers identified set out the historic and policy background to service user involvement but then question the application in practice. The paper by Truman and Raine (2002) is typical of many. The study was set in England and it set out to explore the experience and meaning of service user involvement in a community mental health project. The service was exercise based and had been relocated from a hospital based site to the community setting; the service received statutory funding. The study was participatory and qualitative and used focus group and semi-structured interviews. All the interviewees were service users using the community service. The study

identifies: the importance of the organisational context of the involvement, factors which encourage meaningful participation, barriers to involvement and issues of sustainability.

The concept of empowerment is a recurring theme in the papers identified. The World Health Organisation (WHO) in its statement on user empowerment in mental health describes it thus:

> *Empowerment is an important element of human development. It is the process of taking control and responsibility for actions that have the intent and potential to lead to fulfilment of capacity. This incorporates four dimensions:*
>
> *1. Self-reliance*
>
> *2. Participation in decisions*
>
> *3. Dignity and respect*
>
> *4. Belonging and contributing to a wider community.* (WHO, 2010)

An American study by Linhorst et al. (2002) explicitly explored empowerment through participation in care planning. The study was qualitative and used a review of documents and focus groups of staff and clients to identify the barriers and conditions required for successful involvement in care-planning. It was set in a psychiatric hospital providing long term care to "people with severe mental illness". The study involved 72 clients and 114 staff (working at all levels of seniority). The study identified a range of ways in which care plans were constructed from plans written entirely by staff and given to clients to sign to those that were jointly developed, with the clients' goals driving the process.

An article exploring the nature of partnership and empowerment in mental health (Braye and Preston-Shoot, 1993) explicitly explores the power relationships between service users and professionals with a view to providing frameworks for empowering service provision. The paper is written from a UK policy perspective. The first framework identified is power and inequality, recognising the structures, behaviours and attitudes that underpin this; the second is internalised oppression, which exposed some of the ways in which the disempowered collude with the oppression; the third is choices for practitioners, and the actions they can take to move toward empowerment in the face of inequality and internalised oppression. Although the paper is not based in a real world practice setting, it reaches a number of conclusions about how practice can develop to work with people with mental health problems in an empowering way. These include reaching beyond labels, symptoms and deficits to wider models with a focus on real life goals and facilitating access to people and services outside the mental health system and recognising the system's limits.

Though the process of diagnosis itself can contribute to disempowerment, both because it highlights the illness/wellness difference between service user and professional, and because it exposes the recipient to the risk of discrimination, Kilian et al. (2003) explicitly explores empowerment within a specific diagnosis, schizophrenia. The study aimed to find indicators of empowerment or disempowerment in patients' description and evaluation of their psychiatric treatment. The study was based in Germany and used qualitative interviews with 100 patients with a diagnosis of schizophrenia who were living in a community setting and receiving outpatient treatment, from community teams or private practitioners. The study was unusual in that it set out to measure empowerment by constructing scales on the basis of qualitative analysis. The qualitative interviews

provided a rich source of information and the subsequent work on indicators was useful in ensuring examples I drew from it were both real world and of value.

A number of studies remark on problems of or variation in defining empowerment (see, for example, Walker et al., 2010, Kilian et al., 2003, Linhorst et al., 2002). An American study by Finfgeld (2004) approaches the issue using concept analyses and comparisons with qualitative findings of a variety of approaches to empowerment and measuring empowerment with a view to developing an empowerment model. A framework of the findings organised them into 3 stages: antecedents of empowerment, critical attributes, and outcomes. The concepts classified as antecedents of empowerment focus on what happens before people are empowered, and what needs to be shifted as part of the empowerment process, for example the attitudes and behaviours associated with state of disempowerment. The critical attributes were characterised by active and equal participation of 2 or more individuals, in a mutually respectful way that involves power-sharing and participatory decision-making. The outcomes need to explicitly identify how power is shifted.

These 3 stages were further supported by identifying barriers to empowerment, and what health care providers could do to mitigate them. The barriers identified were consistent with other studies, but the emphasis on the active role that healthcare professionals could take to overcome them, particularly in terms of sharing skills and power, offered practical ideas that could easily be implemented.

This study reviewed concept analyses of, and qualitative research into, empowerment in order to identify how to support (particularly nursing) staff to actively support the empowerment of mental health service users. It was particularly useful in identifying and describing what the study refers to as the cyclical and iterative nature of the empowerment process. The use of the cyclical and iterative model allows the staged transfer of power and knowledge as individuals gain skills, confidence and greater autonomy over time. This process is being facilitated, and actively supported by the initially all-powerful professionals. This approach avoids the risk of professionals feeling that their power is being taken away from them and replaces it with the role of professional as mentor, encouraging individuals to take power for themselves.

Tee et al. (2007) looked explicitly at user participation in clinical decision-making. The study, based in the UK, used co-operative enquiry to work over a two-year period with mental health nursing students collaborating with service users. The cooperative enquiry approach brought together a research team of eight service users, eight nursing students and one facilitator. The study covered three key areas: factors that enable service users to more effectively participate in clinical decisions, and the benefits for students on the decision-making in the presence of mental health service users, and how to apply the learning in value based practice.

Although there are a large number of studies that explore mental health service users' views of services, there are fewer that explore service users' views of service user involvement itself. One such study explicitly asked 31 current and former mental health service users their views of service user involvement (Connor and Wilson, 2006). The study, from Northern Ireland, was qualitative, used a series of focus groups, and took a grounded theory approach to data collection and analysis. Like many other studies, it found that there was a significant variation between policy and practice. Language, information and communication were strong themes in this research, and were thought to be fundamental to effective mental health service user involvement.

Stromwall and Hurdle (2003) explores the framework of psychiatric rehabilitation as an empowerment-based approach to the mental health services. This American article explored the

history, philosophy and practice of psychiatric rehabilitation. Although the language of psychiatric rehabilitation is more familiar in America than UK or elsewhere in Europe, the concept is entirely analogous with the recovery concept which is in widespread use. The article highlights the importance of maintaining a focus on an individual's strengths rather than treating illness or symptoms. The components of psychiatric rehabilitation include practical development of a range of skills that can be applied to various areas of people's lives. These include practical skills, interpersonal skills, vocational skills, budgeting skills and parenting skills.

In addition to the studies that focus on what staff and services can do to build service users capacity to be more actively involved in their own care, there has been increasing interest in what people with direct personal experience can do for themselves and each other. Self-help, self-management, and self-advocacy tend to be more independent of statutory services. Self-help approaches to mental health have been established for many years. One American study acknowledges the growing importance of self-help over 20 years ago (Segal et al., 1993). This study marks the philosophical shift from institutional care, the approach that dominated services for people with severe mental ill-health through the rise and fall of the anti-psychiatry movement to a more independent approach. It introduces what we now think of as the social model of disability, builds on the culture of empowerment, but is firmly grounded in the practical business of what people can do for themselves. Later developments in self-management can be traced directly to this self-help movement.

Self-management has developed from the self-help movement but is characterised by a more structured approach. Self-management is used widely in long-term physical health conditions, but less well established in mental ill-health. I have a particular interest in self-management and have developed a national programme of self-management training and peer support in Wales (described in detail in Crepaz-Keay and Cyhlarova, 2012, Crepaz-Keay, 2010). My work has built on models originally developed by Stanford University in the United States and then in the UK by the Expert Patient Programme. An Australian study, used a patient centred care approach (the Flinders model) (Lawn et al., 2007). The Australian study involved 38 patients with serious mental illness, the Welsh intervention worked with over 650 people who had used secondary mental health services. The Welsh intervention was entirely developed and delivered by current or former mental health service users, whereas the Australian intervention was clinician led. Both these studies suggest that self-management has an important role to play in involving people in their own care.

Self-management and self-help are useful techniques for ensuring people are more involved in their care and treatment. One of the blocks identified (by, among others, Bogg (2010) and Linhorst et al. (2002)) is that sometimes because of an illness or a heightened state of distress, people are unable to articulate their needs, making it almost impossible to become involved in their own care. A number of tools, however, do exist to enable people to express their needs or service preferences in advance. One such tool is advanced directives, sometimes known as living wills. An American study explored the introduction of advanced directives and assessed their impact on coercive crisis interventions (Swanson et al., 2008). The study used quantitative analysis, which compared two cohorts of people with severe mental illness: 147 of whom had completed advanced directives; and 92 of whom had not. The study identified six different coercive crisis interventions and followed up participants at six months 12 months, and 24 months. The study found that completion of an advance directive was associated with lower odds of coercive crisis interventions.

Table 2.1, below shows the specific examples of involvement selected from the literature as potential indicators of involvement at an individual level as presented in the first Delphi round. The

numbers attached to each example correspond to the response number for question one in round one of the Delphi study.

Table 2.2 - Delphi round 1 potential indicators of involvement at an individual level

1. People using services identify their own needs (Truman and Raine, 2002)
2. The service/treatment goals are set by service users (Linhorst et al., 2002)
3. The service/treatment goals are life orientated rather than symptom orientated (Braye and Preston-Shoot, 1993)
4. The service/treatment goals are jointly set by professionals and service users (Linhorst et al., 2002)
5. People have a choice of services/treatments (Kilian et al., 2003)
6. People have the positive and negative effects of treatments clearly explained (Kilian et al., 2003)
7. Service users are actively trained to achieve treatment goals (Finfgeld, 2004)
8. Professionals actively share responsibility and decision-making with service users (Tee et al., 2007, Finfgeld, 2004)
9. All discussions about services/treatments are in plain English (Connor and Wilson, 2006, Finfgeld, 2004)
10. The service/treatment focuses on the service user's strengths and potential (Stromwall and Hurdle, 2003)
11. Service user led self-help groups are promoted by the service (Segal et al., 1993)
12. People are encouraged/trained to engage in self-management (Crepaz-Keay and Cyhlarova, 2012, Lawn et al., 2007, Crepaz-Keay, 2010)
13. People are actively encouraged to find their own sources of support (Braye and Preston-Shoot, 1993)
14. Mechanisms for advanced decision-making (for example advanced directives or crisis cards) are offered (Swanson et al., 2008)

2.6.3 Operational level

In order to identify useful literature at the operational level, all searches include the term "involvement" (except for "peer support" where involvement is implicit) as well as "mental" (the full list of potential indicators at an operational level, drawn from the literature, is shown in tables 2.2 – 2.6, below).

- Training
  searching on "training" in abstracts returned 285 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 32 papers worth further consideration.
- Education
  searching on "education" and "NOT training" (to avoid duplication) in abstracts returned 299 papers. Applying the major heading filter "consumer participation", removal of duplicates and an initial review of abstracts against my exclusion criteria left 15 papers worth further consideration.
- Peer support
  searching on "peer support" in titles returned 25 papers. Removal of duplicates and an

initial review of abstracts against my exclusion criteria left 22 papers worth further consideration.

- Monitoring
  searching on “monitoring” in abstracts returned 90 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 5 papers worth further consideration.
- Recruitment
  searching on “recruitment” in abstracts returned 33 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 3 papers worth further consideration.
- Service provision
  searching on “services” against major subject headings “consumer participation” and “mental health services” returned 188 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 52 papers worth further consideration.

Allowing for papers that appeared in more than one category, review of the abstracts identified a total of 94 papers which were reviewed in greater detail.

The most well developed area of service user involvement is involvement at an operational level, in the day to day running of services. When the focus moves from the individual to the operational, the nature of power imbalances changes. The interface becomes that between an individual mental health service user and an organisation. To redress these power imbalances and make involvement effective, the organisation and its behaviour needs to be broken down into manageable pieces.

This can be done in a variety of ways, and though this is by no means the only possible subsets, the following are suggested by the literature: training, support and payment for involvement, staff recruitment, education and training, service delivery and evaluation, involvement mechanisms and impact of involvement (Braithwaite, 2006, Lea, 2006, Thornicroft and Tansella, 2005, Minett, 2002, Truman and Raine, 2002, Barnes and Shardlow, 1997).

Training, support and payment for service users to be involved

In order for individuals to be effectively involved with organisations, they need adequate preparation and support. The level and nature of support offered for involvement varies significantly. I have reviewed a number of studies which identify some of the support on offer.

One initiative that applied service user involvement to service development was the Acute Solutions project, which ran for three years from 2002. Led by the [then] Sainsbury Centre for Mental Health and in partnership with the Department of Health, The Royal College of Psychiatrists, the Royal College of Nursing, the NHS Confederation and the College of Occupational Therapists. It aimed to find ways of improving the quality of care offered by acute psychiatric inpatient wards for working age adults (Braithwaite, 2006, cited in Lea, 2006). Lea (2006), a service user trainer explored the practicalities, challenges and benefits of mental health service user involvement in one of the most challenging settings, the acute ward. The paper is relatively rare in being written solely by a service user. Despite being from this perspective, the paper acknowledges the significant challenges staff face in this environment; noting that without this acknowledgement, barriers to service user involvement increase. The paper brings together both service user and staff views of the motivations for, benefits of, and barriers to involvement and extracts some principles. It then develops some recommendations for ensuring effective service user involvement.

One of the more controversial components of support for involvement is the area of payment. This covers out of pocket expenses, opportunity cost and additional remuneration for involvement. There are two issues that make this difficult: philosophical issues and practical issues. The National Institute for Mental Health in England (NIMHE) was a government funded national body established as a national resource to encourage best practice in mental health across England. Following a major review of the effectiveness of mental health service user and carer involvement (HASCAS, 2005), NIMHE (by then a part of the Care Services Improvement Partnership (CSIP)) developed and produced Valuing Involvement: payment and reimbursement policy guidance (McKenna and Scott, 2007). Although not a research study or academic paper, this document remains one of the most significant pieces of work in the area of payment; not least because it had the potential to influence every mental health service provider in England. Although it did not constitute government policy, it did reflect Department of Health thinking. The document combined a good, well research philosophical approach to payment with the technical information required to ensure payment policies were consistent with complicated rules for people receiving statutory benefits. The document covers principles for payment, roles and responsibilities, expectations, draws a distinction between paid roles and voluntary roles, covers regular involvement and one off events, benefits rules, and sources of advice for more detailed information. It also included a variety of then current forms and template agreements. Although no longer current, it remains an excellent starting point for anyone struggling with the complexities of payment for involvement.

One of the closest recent equivalents to Valuing Involvement (McKenna and Scott, 2007) is "What you need to know about payment: an introductory guide for members of the public who are considering active involvement in NHS, public health or social care research (INVOLVE, 2011). Although the focus is on involvement in research and the target audience is members of the public rather than explicitly mental health service users, the lead author, Alison Faulkner, is a highly regarded survivor researcher and the resource is entirely applicable to broader mental health service user involvement. Like Valuing Involvement, this is not a research study, but it was written for people who want to get involved and in itself offers support so that people can get involved from a position of some knowledge about the facts, policies and practicalities of being involved and being paid for it. This document also draws a distinction between out of pocket expenses and remuneration. Although it is not as comprehensive as Valuing Involvement, it is more up-to-date and provides one of the best current texts on the matter. This document acknowledges that not everyone who gets involved wishes to be paid; but it highlights issues arising even when no payment is taken for involvement. In addition to addressing "notional earnings" rules (potential earnings decline may be considered earnings as if they had been accepted for the purposes of calculating the impact on benefits); it clearly articulates principles and practice around expenses for involvement, so that people are not financially disadvantaged by getting involved.

Table 2.3, below shows the specific examples of involvement selected from the literature as potential indicators of involvement at an operational level in relation to support for involvement as presented in the first Delphi round.

Table 2.3 - Delphi round 1 potential indicators of involvement at an operational level, support for involvement

1. People involved are supported meet together regularly (Lea, 2006)
2. The organisation has a policy on payment for involvement (McKenna and Scott, 2007)
3. Training is offered for people who get involved (Lea, 2006)
4. People are offered payment for their time (Gregor and Smith, 2009)
5. People have their expenses paid at time of, or after the involvement (INVOLVE, 2011)
6. People have their expenses paid in advance (INVOLVE, 2011)

Involvement in staff recruitment, education and training

Mental health service users have been involved in the education and training of professionals for over 20 years (see a guide based on a training course developed for social workers, see Crepaz-Keay et al., 1997). Much has been written and published in this area, covering a range of professionals, different settings and different approaches.

Basset and Evans (2009) places service user involvement in training, education and development in a national policy context. The paper provides a review of England's National Framework for Mental Health, on the 10th anniversary of the government's overarching framework for its mental health policy over the subsequent decade. The paper includes case studies of three strong examples of service user led organisations who were involved in the planning, delivery and evaluation of training. Between them, the three organisations have developed their own training packages and publications; and provided training for national and local government departments, the statutory sector, the voluntary sector and individuals. This paper highlights what service users can achieve independently.

Benbow et al. (2011) explores the process of developing, delivering and evaluating a post-graduate educational programme aimed at professionals working in health, social care and related fields for older people with mental health problems. The study was based at an English university, and used written evaluation and focus groups of students and service user/carer teachers to analyse the impact of the programme. The programme was developed by a small curriculum group which included a service user, a carer and voluntary sector representatives. This group used design focus groups to consider the course content. A training workshop was offered to potential service user and carer teachers. Anonymous feedback was submitted after each teaching session and focus groups for students and for teachers were held on completion of the module. All service user and carer teachers taught alongside a professional tutor. The process was evaluated positively by both students and teachers.

Gregor and Smith (2009) explore what the authors call "the emotional experience of training" as part of a qualifying degree for an English university. The study uses a psychodynamic framework to analyse the emotional impact of involvement on service user, lecturer and students. The paper was co-authored by a service user and lecturer, who developed and delivered the module as part of the university's BA (Hons) in Social Work. The paper explores the expectations of the professional lecturer, the service user lecturer and the students with respect to service user involvement in the module; their respective roles and responsibilities; the emotional labour involved in delivery; issues of knowledge; organisation expectations; and practical considerations. Although the paper makes no recommendations, it provides a useful understanding of the psychodynamics of service users' relationships with others in the involvement process, in this case a professional lecturer and

students seeking to become professionals; it is clear from the paper that the lead responsibility remains with the professional lecturer.

Some involvement also exists in the selection or recruitment of students for courses. A study by Rhodes and Nyawata (2011) reviewed the involvement of service users in the selection of nursing students for a course at an English university. Historically students had been selected by academic staff and health professionals, using group interviews, tests and one-to-one reviews. The study reviewed the introduction of service user involvement to the process, initially in all parts of the process but ultimately only in the group interview part. The study used a mixed method research design. The views of candidates, service users and academics were recorded: candidates through questionnaires on the day of the selection process, service users and academics by semi-structured group interviews. The study found that involvement increased the candidates' understanding of expectations in nursing practice and also the potential that service users have (rather than seeing them as recipients) and that it was useful for service users themselves to be involved in the process. From a service user perspective, the experience was positive and they felt that they had genuine influence on the process, some reported being underprepared. The academics, though initially sceptical, agreed that the involvement was of benefit to both the process and the candidates. Although the study was expressed in terms of service user involvement, only one of the four people involved was involved solely on the basis of being a direct service user, two were carers and one had both roles – the failure to draw distinctions between service users and carers is unfortunate, as the carer and service user experiences of nursing offer different perspectives.

While service users can be involved in the whole process of developing, delivering and evaluating training and education initiatives (as reported in Benbow et al., 2011, above), this is not always the case. A review of service user involvement in the professional education and training of mental health practitioners (Higgins et al., 2011) set out to explore progress in the field as expected by the country's Department of Health and Children, and its Mental Health Commission. The study used an exploratory descriptive design. Views were sought from psychiatrists, nurses, social workers, psychologists, occupational therapists, and speech and language therapists. Questionnaires with closed and open questions were distributed by post to course coordinators for 227 course across 31 educational institutions. After returns and some exclusions, 137 completed questionnaires were analysed. Service users were involved in 50 of these courses (37%); the greatest area of involvement by far was found to be teaching with 40 courses (29%); 17 involved service users in course design (12%); 11 in evaluation (8%); and only 7 (5%) and 4 (3%) in student assessment and selection respectively. Approximately half (41 out of 87) of those courses that did not currently involve service users reported that they intended to in future. This study identifies the importance of involving service users in all aspects of the training and education process but also highlights the gap between policy and practice.

As has been identified in many of the studies reviewed, involving mental health service users in all parts of the education and training process is a significant challenge. One English school of nursing and midwifery has established diverse initiatives in an attempt to engage service users more fully in professional education. Lathlean et al. (2006) describes the three initiatives in a paper reporting a symposium presenting the three initiatives. The three initiatives were: a service user and carer reference group; establishing the post of service user academic; and a co-operative inquiry of service user and student participation.

The reference group contributes to curriculum design, teaching sessions, research proposals and student facing initiatives. The post of service user academic is relatively unusual in the UK although the role of consumer academic exists in Australia (Happell et al., 2002, cited in Lathlean et al., 2006).

The role of the service user academic is to provide meaningful user-led experiences to increase the impact of user perspectives on students. The post evaluated using a case study design involving 35 students, six members of the service user group and ten other academic staff. It was found to have many positive outcomes, not least by portraying service users in an expert role.

The cooperative inquiry was a study about the participation of mental health service users in the clinical practice decisions of mental health student nurses. It was underpinned by three key concepts: anti-oppressive practice, contact theory and moral development. This approach has shared the power inherent in research with people typically in less powerful positions (service users and students).

Using these three approaches enables both a greater number and greater diversity of people to be involved in the design, delivery and evaluation of the professional training and education that the school provides.

Though service user involvement in assessment is relatively unusual (Higgins et al., 2011), one UK university has used action research to implement and review this approach. A study by Bailey (2005), explores the impact of service users contributing to the assessment of professional competencies of students on the university's MA in community mental health. The assessment process used a portfolio presented by course participants to demonstrate their professional competencies. The study integrated action research into the assessment process. The preparation of potential service user assessors was comprehensive, consisting of: a half-day workshop, an application process, a second workshop which had a focus on how the evidence portfolios were to be compiled. Following this, the service users marked the portfolios and were then given a further half day debriefing. Every stage of this was documented to form part of the study. This was complemented with a focus group of participants who had been assessed to include their experience in the process. This study demonstrates the potential of service user involvement and provides a model of how to support and review it to everyone's benefit.

Most of the involvement set out in this section so far took place in academic institutions or in the education and training process. There were also a number of studies that looked at involvement with staffing issues in a service setting settings. One such (Diamond et al., 2003) took a detailed look at a local rehabilitation service in England. The study explored the implementation of existing service standards relating to service user involvement; examined areas for improvement; and considered the impact of involvement. The study was conducted by a local service user research collaborative, working with a clinical psychologist. The service user group used the principles of User Focused Monitoring (Kotecha, 2003) and was supported by the local NHS trust to undertake this type of service review. The study used a questionnaire designed by the researchers, in an audit style based on 11 of the existing service standards which related to involvement. The questionnaires were completed during face to face interviews: two different staff from each of sixteen teams were invited to take part and 27 interviews were conducted by pairs of interviewers from the service user research group. The results graded standards by proportion of services meeting each standard. Where at least 70% of services had implemented a standard, it was classed as "successful", others above 33% as "established" and below 33% as "modest". The results indicated that involvement in staff training was the most widespread with 92% of services reporting this with recruitment second, at 78%. Despite some implementation of involvement in recruiting, this was not reflected in subsequent involvement in induction which was implemented in only 26% of services. Involvement in all parts of the recruitment process, from job description, through selection process to final appointment decision, was regarded as a significant and important success.

Table 2.4, below, shows the specific examples of involvement selected from the literature as potential indicators of involvement at an operational level in relation to involvement in recruitment, education and training as presented in the first Delphi round.

Table 2.4 - Delphi round 1 potential indicators of involvement at an operational level, involvement in training and education

1. Service users deliver training independently or professionals or other trainers (Basset and Evans, 2009)
2. Service users deliver training in partnership with professionals (Benbow et al., 2011)
3. Service users contribute to a professionally led training session (Gregor and Smith, 2009)
4. Service users contribute to design the training curriculum (Higgins et al., 2011)
5. Service users contribute to the development of training (Lathlean et al., 2006)
6. Service users are part of professional development assessment process (Bailey, 2005)
7. Service users contribute to staff job descriptions (Diamond et al., 2003 suggests involvement in all parts of the recruitment process but not explicitly job descriptions)
8. Service users are involved in shortlisting candidates (Diamond et al., 2003)
9. At least one service user is part of an interview panel for all staff recruitment (Rhodes and Nyawata, 2011)

Involvement in delivering and evaluating services

Although mental health service user involvement in the selection, education, recruitment and training of mental health professionals is important in itself, its primary purpose has to be leading to service improvement. One study set out to explicitly explore impact of involvement in nurse education on their practice. Rush (2008) attempted to establish a link between education and practice using a "realistic evaluation" methodology to track and establish mechanisms for transformative learning. A total of 26 student nurses participated in semi-structured interviews and 7 of them took part in a group interview. Mechanisms identified were: lived experience, emotions, role reversal, and reflection. The different status of service users and academics in the teaching and its potential impact on the benefits is noted. Changes in practice were informed by hearing first hand examples of experiences that could have been improved by nurses. These often included examples where the student consciously reframed their relationship with their patients as human interactions with a focus on time and manner of communications, particularly around medication, treatment and informed choice; and the differences between perceiving something as symptoms or human experience. Twelve service users also took part in the study but their data were analysed separately as the purpose was to establish the impact on the nurses' practice. I think these views could easily have been included to give a more balanced interpretation.

Further examples of the benefits of involvement in training and education on professional practice and service user experience are found in a number of literature reviews. A review by Repper and Breeze (2007) was cited in many of the studies I have reviewed; it covered 38 papers in detail and structured findings around methods of consumer involvement and evaluations of consumer involvement with more specific subcategories in each. This study was useful both for highlighting existing research (and its limits and omissions) and for its systematic theming of the findings. The studies reviewed and the analysis support many of the suggested indicators in my Delphi study. There are also a few omissions from this review that could have been included and it is not clear how the selection criteria stated resulted in only these 38 papers. The focus on the role of service users as producers of materials is useful, as is its noting of some of the difficulties of jointly

producing materials (Reynolds and Read, 1999, cited in Repper and Breeze, 2007). This learning can be applied beyond the training setting. Many service users have talked about the importance of producing information for others but this topic is not really picked up elsewhere in the literature.

It is increasingly common for service users to take on paid roles in service provision as servicer user experts. In Australia this role is commonly known as consumer consultant and Middleton et al. (2004) investigated the experience of consumers in a regional public mental health programme. The region has over 60 people working in these roles. They are employed under the same conditions as other state employees and are accountable to their employers, not to service users. The paper outlines some of the barriers to consumer participation and sets out to fill the identified gap in understanding how the consumer consultants experience the role. 10 of the 60 were interviewed using a semi-structured interview and analysed by themes which included areas of difficulty, areas of influence and analysis of, and impact on, services. The feedback analysis suggested services could be characterised as either "rigid and unresponsive" (red) or "collaborative and enabling" (green). The study also usefully highlighted a range of characteristics which could easily be seen as potential indicators for my Delphi study. The study was small scale, but benefitted from having a strong service user focus that was not diluted or over-interpreted by professionals or academics.

Peer support is becoming widespread in the UK (and indeed elsewhere). There are a number of models and approaches being used. I wanted to use this Delphi study to gain insight into the relative merits of three key characteristics of different types of peer support: who leads the peer support services; whether peer supporters are paid workers and whether people can choose their peer supporter. Peer support can be clearly linked to self-help initiatives with a very long history, but the language of peer support and peer support as a defined role in services is much more recent. An Australian study (Franke et al., 2010) evaluated a training programme designed to prepare service users for a peer support role. The evaluation was two stage, with the first stage using written surveys, telephone interviews and a focus group, and the second stage, ten months later, based on a thematic analysis of 25 interviews with peer workers, their managers and colleagues. The main objective of the course was stated as being to secure paid employment for peer workers, and the evaluation suggested it achieved this. Overall, the evaluation found that 103 from 140 (73.5%) course members achieved an employment outcome, 73 (52.1%) of whom were in paid roles. The success rate increased over time (i.e. the longer after completion of the course, the greater the employment rate). The peer support model was clearly professionally led but it is not clear what role the peer workers played in the study, beyond being study participants.

Two recent reviews of peer support provide different pictures of the state of peer support in the UK at the moment, reflecting the difference that the study approach can make to conclusions. Repper and Carter (2011) reviewed papers relating solely to peer support workers in statutory settings. In service user involvement terms, this means that the degree of involvement is limited by the nature of the statutory service. The review had a focus on studies which sought to establish the benefits of peer support; 38 papers were included. As well as trying to establish the benefits of peer support, the studies identified a number of challenges. Benefits found included possible reduction in admission rates, increased empowerment, improved social functioning and reduced stigma as well as benefit for the peer support workers themselves. The challenges identified came largely from the unusual dual role that peer support workers had, being both paid staff and peers. Power, boundary issues and maintaining a role distinct from other staff all proved challenging. The study did not address an emerging philosophical issue which is the nature of "peer-ness"; and in particular whether one ceases to be a peer when one becomes a paid member of staff accountable to a statutory employer.

Faulkner and Kalathil (2012) was original qualitative research which did not limit the scope to statutory peer support. Though this study appeared to take a much broader view of peer support, it may actually have taken a tighter view of who a peer is as this was defined by service users themselves rather than by a statutory organisation (I should note that I contributed comments to the report during its drafting and am credited). The study used an online survey, site visits and telephone interviews; 44 people responded to the survey and nine peer support services were visited or interviewed. One of the most significant differences between Repper and Carter (2011) and Faulkner and Kalathil (2012) is the approach to what constitutes a peer: although the former mentions definitions, the review accepts that a peer support worker is a peer, by definition; whereas the latter explicitly asked research participants the question "what constitutes a peer?" and reports the views expressed. Characteristics that were thought important when considering someone to be a peer included: shared ideas about what recovery means (76%), shared understanding of a particular diagnosis (73%), and shared views about medication and treatments (58%). The report found similar benefits and challenges to the review, but highlights issues around peer support that may be difficult to address in purely statutory settings where it is not clear how much choice service users have over who is chosen as their peer.

It is now widely recognised that making a simple distinction between people's physical and mental health is unhelpful. Taking a more holistic approach to addressing mental ill-health in a broader health context is part of most recovery models. Wellness Recovery Action Planning (WRAP) has been established in the US for some time and a number of WRAP initiatives now exist in the UK. A study by Cook et al. (2009) examined the initial outcomes of a WRAP based self-management programme in the US. 80 people with serious mental illnesses were interviewed at baseline and one month after completion of the intervention. The study found significant improvements in most areas but an unexpected fall in empowerment. The physical health benefits were significant, alongside other benefits beyond significant symptom reduction. The follow up period of one month is too short to establish any long term benefit.

An Australian study into peer support also found potential benefit in physical health. Bates et al. (2008) trialled a peer support intervention which referred 32 clients, of whom 25 elected to receive peer support. 20 participants reported increased physical activity, 8 reported weight loss 7 improved diet and 5 ceased smoking. The trial had no control group and the period over which the improvement took place is not reported, so though the findings are interesting it is not possible to draw conclusions from it.

One of the limitations of many of these studies, from a service user involvement perspective, is that success or failure is usually judged by clinicians or academics. User Focussed Monitoring (UFM) was developed to address this issue (the process of UFM is described in Kotecha, 2003). This is not a study or research project, rather it is an important approach to ensuring that services reflect the needs of their service users from a service user perspective. I have included the use of UFM as a potential indicator of service user involvement on that basis.

Table 2.5, below, shows the specific examples of involvement selected from the literature as potential indicators of involvement at an operational level in relation to involvement in delivering and evaluating services as presented in the first Delphi round.

Table 2.5 - Delphi round 1 potential indicators of involvement at an operational level, involvement in delivering and evaluating services

1. Services provide clear information about medical treatments written by professional in clear language (Rush, 2008)
2. Service users contribute to the production of official information (Repper and Breeze, 2007)
3. Service users are provided with information written by service users (Repper and Breeze, 2007)
4. Service user involvement is led by a service user in a paid role (Middleton et al., 2004)
5. Peer support is part of the service but led by professionals (Franke et al., 2010)
6. Service has peer workers who are paid employees (Repper and Carter, 2011)
7. Service users choose their peer support (Faulkner and Kalathil, 2012)
8. The service addresses the physical health needs of service users (Cook et al., 2009, Bates et al., 2008)
9. User focussed monitoring is in place (Kotecha, 2003)

Mechanisms for involvement

Mental health service user involvement in mental health services in the UK built steadily throughout the 1980s, with the establishment of local and national organisations run by and for mental health service users. By 1990, this was reflected in national legislation. The 1990 NHS Community Care Act (DH, 1990) made two changes that had a significant impact on service user involvement: it introduced the "purchaser provider split" which separated the functions of commissioning services from providing services, establishing the consumer culture; and it introduced a duty to consult "such voluntary organisations as appear to the authority to represent the interests of persons who use or are likely to use any community care services within the area of the authority or the interests of private carers who, within that area, provide care to persons for whom, in the exercise of their social services functions, the local authority have a power or a duty to provide a service".

A study by Bowl (1996) placed the act in historical context and explored evidence of how the interests of service users were represented within community care services. The evidence came from surveying social service departments (the agencies responsible for the implementation of the duty to consult) and interviews with 135 service users. The study uses a combination of telephone surveys of principle officers in 31 local authorities and 135 service users from 9 services and 6 user fora. The information from service users was gathered through observation, group interviews and individual interviews.

Three "dimensions of user involvement" are explored: the interests represented, the form of representation and the extent to which power is transferred. The study identifies the three interests as service users, carers and the wider public: this distinction is particularly important as it acknowledges that the interests may well be conflicting; it is also the precursor to the subsequent terminology patient and public involvement (PPI). It is also where many studies fail to draw distinctions (what Rhodes and Nyawata, 2011 call service user involvement is predominantly carer involvement, for example). The forms of representation is the most useful dimension for my Delphi study. It provides one of the first widespread analyses of what was actually happening in terms of service user involvement on the ground following the legislative and policy changes. Many of the examples from the operational, and some from the strategic level of my study, are first referenced in this study, along with some of the challenges and opportunities presented by each. The final dimension is power transfer. This remains the most challenging area of service user involvement, both in practice and assessment of impact. While many studies contrast the variance between policy and practice (or rhetoric and reality), this study unpicks it in more detail. The study set a high

standard for future wok on analysing involvement and despite its age remains an important, and much cited piece of work.

Rutter et al. (2004) examined two detailed case studies of service user involvement in London. The case studies were selected against criteria developed by a research group which included mental health service users. Service user involvement in 2 NHS trusts was examined in great detail. Between them, the two trusts serve a population of 1.7 million people. Interviews were completed with 13 service user groups, 9 voluntary sector groups, and 27 staff. The objective limits and goals of service user involvement were tabulated from a range of perspectives. The study was particularly effective at drawing out the differences in perceptions of service user involvement from different types of staff as well as between staff and service users. One example that my experience suggests is widespread but rarely appears in literature, is the difference between how negative comments of service users' experiences are seen as fundamental to involvement from the service user perspective, yet often seen as inappropriate from the service provider perspective. It also recognises the value of mental health service user representatives doing outreach work to collect and collate the views of other service users and then contributing them. This study is remarkably detailed, provides a significant number of examples of how service users can be involved and in what; and could be regarded as an essential guide to service user involvement for any large-scale organisation wishing to take it seriously.

One specific approach to involvement is the service user panel. A panel is a group of people established for, and limited to, a particular purpose. A Canadian study by Perreault et al. (2010) described a panel comprised of psychiatric outpatients used to assess client satisfaction with the psychiatric institute. One useful aspect of the study is an assessment of the strengths and weaknesses of the range of tools used to establish what the study refers to as client satisfaction. Panels are a resource for the body that establishes them, rather than a service user developed initiative. This limitation has both advantages and disadvantages: the key advantage is a clear sense of purpose, a group with a particular job to do; the key disadvantage is that the close relationship between the panel and the service may reduce the validity of the panel's findings. The study is well constructed and does a good job of describing the panel process, its strengths and limitations.

Many involvement initiatives revolve around the meeting as the mechanism for involvement. This is seen as a limitation, not least because meetings tend to favour those who are more articulate in group settings. This can easily disadvantage mental health service users in mixed meetings, and some service users in service user only settings. This limitation can be addressed in a number of different ways, and Fitzgerald et al. (2011) explored the use of the serious game format as an alternative involvement mechanism with patients in a low secure setting. The study describes the game mechanism used to engage an historically marginalised patient group in the redesign of the low secure unit they are detained in. The study offers a good description of an innovative approach to involvement that would help offer alternatives where meetings may exclude some participants from active involvement.

Even within meeting settings, it is possible to use structures that overcome some of the problems inherent in traditional meetings and focus groups. A study by Perry and Linsley (2006) explores the use of nominal group technique (NGT), as a structure to avoid some of the less constructive behaviours that can occur in meetings. Although the study describes how the technique was applied to the exercise, it does not analyse the impact of the technique itself. It does, however, demonstrate that the technique produces outcomes in consultation exercises. Anyone wishing to replicate the technique as an involvement mechanism would probably find this paper inadequate in establishing whether NGT is the appropriate tool, or not.

As well as structuring meetings differently, it is possible to bring people together in completely different ways to enable them to express their views. A study by Barnes et al. (2006) reviewed the use of a storytelling workshop as an alternative approach to enable a group of women to contribute to the production of an expert paper studying women-only mental health services. The study described the theoretical underpinnings of narrative, rhetoric and emotional exchanges as a contribution to building knowledge based on real-world experience. The workshop was attended by over 50 women; and the study describes the event, its atmosphere, and some of the information elicited from it. Although the study clearly welcomes the notion of creativity, and the importance of making involvement a creatively satisfying experience; it is unclear from the study how much influence the event had on the content of the actual paper. This makes it rather difficult to establish, from this study, the effectiveness of storytelling as a mechanism.

There are also an increasing number of alternative mechanisms for engagement that do not require people to be physically present at the same time in the same place. Service user defined outcomes were identified above as an important part of people being more involved in their own care. A study by Perry and Gilbody (2009) used the Delphi process to enable people from low secure hospital wards to engage in a consultation process that could not have involved them if it had required physical presence. This study was particularly helpful in explaining the value of the Delphi process in helping to reach consensus in comparison with focus groups and other methodologies.

There are a number of other mechanisms that offer a range of opportunities for remote involvement, although many of these are too recent to show up in published literature, I have included them as potential mechanisms alongside Delphi to emphasise that remote involvement is likely to be increasingly important.

Table 2.6, below, shows the specific examples of involvement selected from the literature as potential indicators of involvement at an operational level in relation to mechanisms for involvement as presented in the first Delphi round.

Table 2.6 - Delphi round 1 potential indicators of involvement at an operational level, mechanisms for involvement

1. The service has a regular meeting that service users can attend to get involved (Bowl, 1996)
2. Decision-makers from services visit service users at service user led meetings (Bowl, 1996)
3. The service has an independent service user panel (Perreault et al., 2010)
4. Some of the service's operational meetings include one or two service users (Bowl, 1996)
5. Games based approaches to involvement are used (Fitzgerald et al., 2011)
6. Meetings are structured to ensure equality of involvement for all participants (Perry and Linsley, 2006)
7. Online, social networks and other remote techniques are offered to enable involvement without physical presence (Perry and Gilbody, 2009, Langlands et al., 2008)
8. Story-telling and drama presented by service users is used as a way to present service user views (Barnes et al., 2006)
9. Service users engage in outreach work to ascertain views of other service users and report back (Rutter et al., 2004)

Impact of involvement

Although mental health service user involvement clearly has value as a process, it is also designed to improve mental health services and their outcomes. A systematic review by Simpson and House (2002) sought evidence of the effects of mental health service user involvement in delivery and evaluation of mental health services. The review explicitly excluded involvement in people's own care and settings that was service user only, for example, self-help groups. It found 5 randomised trials and 7 other comparative studies. None of the studies found negative effects of service user involvement and possible benefits were identified. The review clearly shows that much more evidence of the effectiveness of mental health service user involvement should be sought.

The positive impact of mental health service user involvement beyond service benefit was explored by two further studies. Service user involvement as a mechanism for reducing discrimination and stigma, and policy and practice implications for achieving this, along with the existing legal and policy imperatives driving this were examined in detail by Thornicroft (2006). This extensive piece of work outlined the importance of reframing stigma in terms of ignorance and prejudice. It identified the consequences of failing to address discrimination and set out the key role that service users need to play in anti-discrimination work. One of the important contributions that this work makes is to clearly identify who needs to do what - it is unusual in that it explicitly ascribes a number of roles directly to mental health service users and user groups.

The same author also identified the importance of service user involvement for other reasons in an earlier study (Thornicroft and Tansella, 2005). This study emphasised the importance of service user rated outcome measures. It identified them as one of the most useful indicators of effective services, particularly in assessing how well those services improve the quality of life of the people they serve.

Many studies identify barriers and blocks to effective mental health service user involvement. One of the most regularly repeated criticisms of a range of service user involvement initiatives is that the service users involved are not typical or representative. A paper by Happell (2008b) explored some of the more subtle ways in which professional attitudes that appear to be well-intentioned may actually be polarising opinion both within and towards mental health service user communities in a way that is counter-productive to effective mental health service user involvement. This paper goes beyond straightforward analysis of blocks and barriers to involvement and provides some real world examples of the complications of polarisation and political correctness. This paper provides a useful and timely warning for anyone who is concerned about negotiating real-world difficulties of the redistribution of power that is part and parcel of effective mental health service user involvement.

Table 2.7, below, shows the specific examples of involvement selected from the literature as potential indicators of involvement at an operational level in relation to impact of involvement as presented in the first Delphi round.

Table 2.7 - Delphi round 1 potential indicators of involvement at an operational level, impact of involvement

1. Services demonstrate improved mental health outcomes linked to involvement (Crepaz-Keay, 2006, Bowl, 1996)
2. Services demonstrate improved health outcomes linked to involvement (Simpson and House, 2002, Bowl, 1996)
3. Services demonstrate improved quality of life linked to involvement (Thornicroft and Tansella, 2005)
4. Services demonstrate reduced discrimination linked to involvement (Thornicroft, 2006)
5. Barriers to involvement are identified and reported (Happell, 2008b)
6. Barriers to involvement are identified and overcome (Happell, 2008b)

2.6.4 Strategic level

In order to identify useful literature at the strategic level, all searches included the term "involvement" as well as "mental". I initially limited search to titles and broaden to abstract if the title search returned a small number of useful papers (the full list of potential indicators at a strategic level, drawn from the literature, is shown in table 2.7, below).

- Planning
  searching on "planning" in abstracts returned 207 papers. Applying the major heading filter "consumer participation", removal of duplicates and an initial review of abstracts against my exclusion criteria left 23 papers worth further consideration.
- Monitoring
  although monitoring was used at the operational level, I also included it at the strategic level, where it influences the development of future services. Searching on "monitoring" in abstracts returned 90 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 5 papers worth further consideration
- Commissioning
  searching on "commissioning" in abstracts returned 10 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 2 papers worth further consideration.
- Governance
  searching on "governance" in abstracts returned 16 papers. Removal of duplicates and an initial review of abstracts against my exclusion criteria left 6 papers worth further consideration.
- Service reorganisations
  no relevant results were returned when searching on "reorganisation".
- Policy
  it became evident that searching for service user involvement in policy by search terms was not practical. The volume of returns made distinguishing between involvement in policy and involvement policies too onerous to be useful. Involvement in policy can be extracted from papers found elsewhere in the review.

Allowing for papers that appeared in more than one category, review of the abstracts identified a total of 33 papers which were reviewed in greater detail. A number of these papers addressed

involvement at either operational or individual level as well. This is to be expected, as many of the elements of effective service user involvement have been identified alongside those at the individual and operational level; either because studies have addressed issues at more than one level, or because activities like evaluation and research may themselves have an impact on current (hence operational) and future (hence strategic) services. Those studies previously reviewed will not be repeated, but where potential indicators are drawn from them, they are referenced in table 2.7, below.

Two issues relate exclusively to the strategic level, however: governance and commissioning. It is a feature of many modern service providers that they encourage service user involvement in their governing bodies either through attendance at or membership of boards. Whereas Simpson and House (2002) examined trials and comparative studies, the review conducted by Crawford (2002) included case studies. This gave a much larger number of studies to review and found evidence that service user involvement contributed to changes in service provision, but also concluded that there was no evidence base for a range of effects. The range of involvement mechanisms discovered and reviewed is broad and covers involvement at all levels.

One study exploring the employment of people with a mental illness in mental health services (Grant, 2007) in Canada also identified a range of other roles people were involved in. The study involved a written survey that was completed by 74 community based service provider organisations. The average proportion of employees who had identified having a mental illness was 32% with proportions ranging from 0% to 100% (5 of the organisations were service user run). There was a very high prevalence of organisations with service user board membership (72%). The study identified its limitations, in particular the response rate of 44% was probably highly skewed towards the organisations better disposed towards service user involvement. Even with this limitation, the study provides a valuable insight into the breadth and depth of service user involvement in staff and governance roles.

Changes in the governance of health and social care organisations could itself be having an impact on service user outcomes. One international review (Rummery, 2009) explored how the pressure on resources and increasing demands for services in combination with statutory encouragement of partnerships across health and social care organisations may be affecting the role of, and outcomes for, service users. 76 papers were reviewed, meeting the two key criteria: that they reviewed a collaboration between two distinct services (partnerships) and that they drew conclusions about outcomes. The scope of the review was not limited to mental health, but the analysis and commentary referred specifically to mental health and mental health users throughout. Mental health service users formed the largest single patient group in the review. Overall the review suggested partnership work benefited mental health service users, albeit with caveats, particularly where combined health and social care led to user defined priorities being taken seriously in the planning and delivery of welfare. The review highlighted the complexity of issues at a macro level and indicated areas where more thinking and reflection needed to accompany policy development.

Commissioning in mental health was a function that directly resulted from the purchaser provider split introduced by the 1990 NHS and Community Care act (as mention in discussion of Bowl, 1996, above). Although in theory commissioning should have been established for over 20 years, problems were regularly reported, particularly with its implementation in mental health. A report on the then current state of commissioning in mental health (Forrest, 2005) interviewed key players from a policy and practice perspective, identified a range of successes and challenges for commissioning. The reporting is more journalistic than academic, but gives a reflection of a broad range of

stakeholder views. This includes a clear expression of the importance of involving service users in commissioning.

One important subset of modern governance in health services is clinical governance. Stanton (2006) provided a general review of the role of English NHS boards in the clinical aspects of governance. Clinical governance was an area that took considerable time to establish, with corporate governance coming more naturally to most boards. This review describes the role and responsibility of the NHS Clinical Governance Support Team (CGST) in supporting NHS boards to meet their responsibilities; and introduces the CGST's development programme. The review highlighted the development of the focus on mental health trusts. The paper assumed a high degree of understanding of organisational concepts and processes and should remind those with primarily governance functions of the importance of mental health service user involvement in those processes at all stages.

Pickard et al. (2002) specifically investigated the role of service users in clinical governance. The study used a qualitative design of semi-structured interviews, reviewed documentary evidence and literature across 12 Primary Care Groups/Trusts (PCGs/PCTs). The PCGs and PCTs were purposively selected to reflect varying sizes and geographic factors as well as corporate status (i.e. Group or Trust), 12 Lay board members, 12 chief executives, 14 clinical governance leads, 9 mental health leads, 2 board chairs and an executive committee lead were interviewed. The study identified the then current guidance for mechanisms for service user involvement and used these to guide the interviews. Issues of accountability and representativeness were raised but there was a strong focus in the study on the wider public rather than service user involvement, as it is understood throughout my work. Although it nominally highlights user involvement in clinical governance, it actually offers more on lay membership of boards with little emphasis on either service user involvement or clinical governance.

Table 2.8, below, shows the specific examples of involvement selected from the literature as potential indicators of involvement at a strategic level as presented in the first Delphi round.

Table 2.8 - Delphi round 1 potential indicators of involvement at a strategic level

1. Service users attend the governing body (Crawford, 2002)
2. Several service users sit on the governing body (Grant, 2007)
3. Service users review and report to the governing body (Rutter et al., 2004)
4. Service developments are clearly influenced by user focussed monitoring (Kotecha, 2003)
5. Service users define the purpose and direction of the service (Rummery, 2009)
6. New services are jointly designed or co-produced by service users and professionals (Fitzgerald et al., 2011)
7. Services demonstrate any changes linked to involvement (Crepaz-Keay, 2006, Simpson and House, 2002, Bowl, 1996)
8. Service users are involved in the commissioning of services (Forrest, 2005)
9. Service users are involved in contract specification (Rutter et al., 2004)
10. Service user involvement is explicitly included as part of clinical governance (Stanton, 2006, Pickard et al., 2002)
11. Service users are given the resources required to develop their own services (Bowl, 1996)

2.7 CONCLUSIONS

This chapter has identified mental health service user involvement as a part of UK government policy for over 25 years. I have noted that the implementation of this policy remains variable and attempts to assess its impact are far from complete. I have clarified some of the language used and explained the terms I intend to use.

I have made the case for taking a more methodical approach to assessing effective mental health service user involvement and suggested an indicator based approach as a way forward. I have identified three distinct levels at which involvement takes place, identified key activities within each of these levels and drawn potential indicators of effective involvement from peer reviewed literature.

The next chapter will explain the methods used to take these potential indicators and ensure that the final indicators have meaning and value in assessing effective mental health service user involvement.

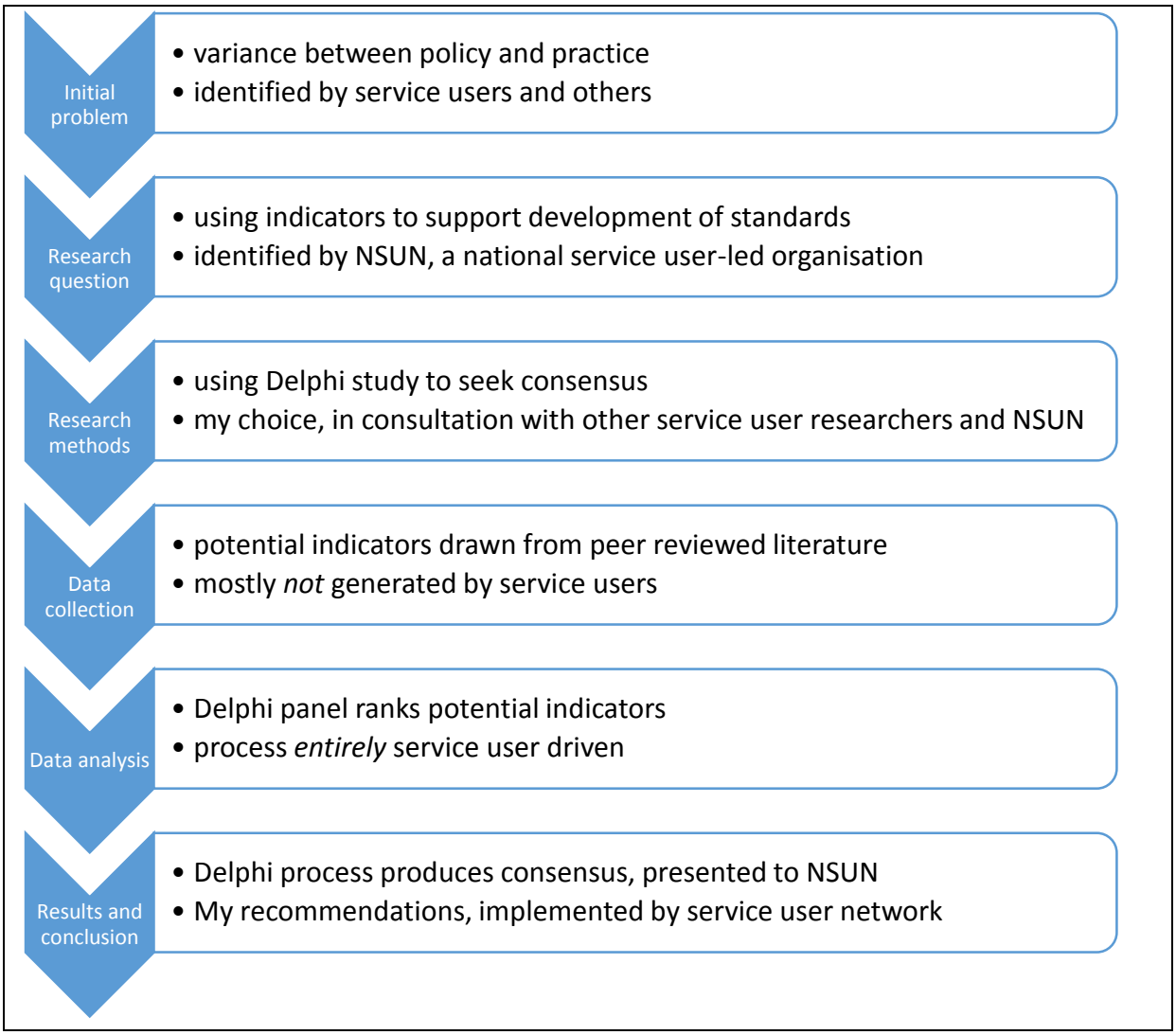
3 RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The previous chapter identified using indicators as an approach to assessing effective mental health service user involvement. I set out a framework from which to draw indicators and identified 64 potential indicators from peer reviewed literature.

One of the challenges with this approach is that the potential indicators are drawn from a body of literature that is not predominantly produced by mental health service users. Much of it does not, in itself even involve service users to a great extent. This issue is discussed in greater detail in chapter 6. In order to address this deficit, I have ensured that the potential indicators are scrutinised by mental health service users who have considerable experience and expertise in involvement and that they reach consensus on the final indicators. This chapter outlines the methodology and methods used to ensure that this process is entirely driven by experienced mental health service users and figure 3.1, below identifies where mental health service users and networks have been involved in this research process.

Figure 3.1 - Service user involvement in process



The presence and priority given to mental health service user involvement identified earlier, the significant increase in mental health service user led research (Faulkner and Layzell, 2000), and the prevalence of outcome orientated services have created an environment favourable to objectively identify effective mental health service user involvement. However, there is still a distinct divide between those who control, design, gate-keep, deliver, regulate, monitor and evaluate everything to do with mental health services and those who use them. On the whole mental health services are still done by one section of society *to* another. In short, sane people describe, define and deal with mad people (see also Sayce, 2000).

In this respect, the mental health service user movement has much in common with feminism (and, indeed, with the experiences and responses of many other disadvantaged groups). People with a psychiatric diagnosis experience discrimination both in society (including higher rates of unemployment, reduced access to financial services and many other experiences of discrimination (Thornicroft, 2006, Johnstone, 1989)) and in the law (whether it is by virtue of legal compulsory treatment, which would be illegal for non-psychiatric conditions, or legal exclusions from rights that are afforded to others). The analysis of feminism as a theoretical perspective (as presented by, for example, Crotty, 2003, and Robson, 2002) has strong resonance with my experience and beliefs.

3.2 RESEARCH PARADIGM

I have taken an emancipatory paradigm which, as Robson (2002) notes, is equally applicable to a range of disadvantaged groups. He sets out four features of the emancipatory paradigm thus:

1. It focuses on the lives and experiences of diverse groups (e.g. women, minorities, and persons with disabilities) that traditionally have been marginalised.
2. It analyses how and why resulting inequalities are reflected in asymmetric power relationships.
3. It examines how results of social enquiry into inequalities are linked to political and social action.
4. It uses emancipatory theory to develop the research approach.

The emancipatory paradigm in disability research was developed following criticism that the then existing paradigms, when used in disability research equated the disability to the individual's impairment. The emergence of the social model of disability shifted the emphasis towards the social situation of the disabled person rather than the impairment and emancipatory research was developed to shift the research focus from researching the impairment and its impact to understanding the relationship between disabled people and society.

> *The development of such a paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge through the scientific method and the gradual disillusionment with the interpretive view of such research as the generation of socially useful knowledge within particular historical and social contexts. The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs whatever levels it occurs* (Oliver, 1992).

Emancipatory research has also been applied more specifically to research involving those who Beresford and Wallcraft (1997) refer to as psychiatric system survivors. Oliver (1997) questions the reality of emancipatory research by asking who owns and who benefits from the research and makes it clear that emancipatory research needs to be owned by and benefit the subjects of the research. The test for my research therefore is encapsulated in the question does this research contribute

positively to the emancipation of people who have used mental health services? In short, does it address and attempt to alter existing power relationships?

3.2.1 Understanding power relationships

Power relationships exist at every level of the relationship between mental health service users and those responsible for funding, developing, delivering, evaluating and regulating those services.

The starting point of the unequal relationship is need. The service user has a need and the professional is there to meet it. One party is giver and one is recipient and the power is with the giver. This power imbalance is reinforced by status and payment. The professional is paid for their part in the relationship, the service user is not. The professional is trained and supported in their role, they are part of a team, they are part of a professional body, the service user is not. The social status applied to a clinical professional is high, the social status of a psychiatric patient is not. Possibly even more significantly, for the professional the transaction is a job, they get to go home afterwards, for the service user it's their life, and they are stuck with it.

These differences are reinforced, in the UK and many other territories, by the law. The 1983 Mental Health Act grants significant powers to a range of professionals that explicitly enshrine power differences. Professionals are legally entitled to assess, treat, detain and restrain on the basis of their professional judgement. Even when these powers are not used; their existence makes the relationship different from most normal human relationships.

The nature of the need itself is another significant power issue. Even if the need is initially identified by the service user, it is defined by the professional, usually through the process of diagnosis. This power imbalance is heightened once a diagnosis is in place as the professional is well and the service user is ill. The nature and degree of this unwellness is defined by the professional. The language used can also reinforce the difference; professional jargon making dialogues unbalanced.

The nature of mental ill-health further reinforces the imbalance. It can make articulating need and communicating clearly much more difficult. This effect can be increased by the low self-esteem associated with mental ill-health. It may also be increased by the negative effects of medical treatments. Many of the "side effects" of psychiatric drugs affect the ability to articulate; some also have a significant debilitating effect on some people.

These power issues at an individual level are reinforced by complicated organisational structures at an operational level. With individual service users facing large complicated organisations that are governed by rules that may not be apparent to the service user. The rise of consumer power in public services in the UK coincided with considerable organisational change moving from a relatively simple linear NHS to a network of commissioners, competing providers, regulators, currencies and tariffs, and patient representative structures. So on the one hand the rights and powers of service users may have grown, but the skills, knowledge time and effort required to exercise them has grown alongside it.

My case for this research being emancipatory is underpinned by the following intrinsic features: the design and approach was influenced by my experience as a member of the service user community, rather than by an outsider looking in; the research participants (the Delphi panel) are cast as experts rather than objects of research; a clear distinction is made between source materials written by people who are not predominantly service users and judgements made on the source materials by people with direct personal experience of service use and service user involvement.

3.2.2 Strengths and weaknesses

There are a number of strengths and weaknesses associated with both the theoretical perspective and methodology chosen.

I believe the key strength is the way the combination of theoretical perspective and quantitative approach work to bridge the gap between the historic positivist approach of psychiatry and the consequential marginalisation and oppression of a large number of people.

The theoretical perspective sits at odds with the objectivist, positivist approach of modern psychiatry, the paradigm that has governed, and continues to govern mental health services. The consequences of this approach are so deeply embedded in the field that all initiative that are based on an alternative theoretical underpinning are treated with a high degree of caution. Further, the notions of evidence based practice and clinical effectiveness that form such a significant part of current health policy take a fairly partial view of what constitutes evidence and effectiveness. I see my approach as helping to improve those two concepts (complementary), but others may see this research as inherently challenging them (alternative).

The emancipatory approach may be seen as antagonistic towards mental health staff, by casting them in the role of oppressor. I do not believe that it is, I consider this to be post-psychiatry not anti-psychiatry. It is true however, that effective service user involvement is about changing the balance of power. This means that service users would be gaining power *at someone else's expense*. I believe that this is only a problem if the people in question see their role as exercising power (rather than, say, improving people's mental health).

I will address these potential weaknesses by being as methodologically robust as possible. One of the reasons I want to be able to assign values to the indicators of effective involvement is my belief that decision-makers are more likely to believe an argument, report, campaign or recommendation if there are numbers attached to it. The issue of engaging staff will be best addressed through engaging a broad range of stakeholders with the process of building and testing the tool.

There will also be challenges from those who do not consider that it is appropriate, or even possible, to put a numerical value on service user involvement. It may even be seen as devaluing the concept to try to do so. I can only confront this potential weakness head on by demonstrating that it is both possible and beneficial to do so. I believe that it may even be necessary to ensure that service user involvement is sustainable for the foreseeable future.

3.2.3 Addressing power relationships

The discussion of research paradigms identified the importance of power relationships in both the history of mental health services and of mental health service user involvement. Power relationships exist in every part of the clinical process and broader service development and provision (Kilian et al., 2003, Linhorst et al., 2002). It is also clear that power relationships exist within mental health service user involvement as well. This has been highlighted by, for example, the predominantly white service user movement in the UK (Wallcraft, 2003), by issues arising in peer support (Faulkner and Kalathil, 2012), and the constant challenge of representativeness in service user involvement (Crawford and Rutter, 2004, Crepaz-Keay, 1996).

Power relationships in involvement mechanisms

For the purposes of recognising power relationships within mental health service user involvement, it is helpful to divide the types of involvement in to those that involve people individually, and those that involve them in some form of group. Whilst both of these arrangements are influenced by power relationships, the influences are different.

Where people are involved individually, the power relationships between the person being involved and the person controlling the involvement needs careful consideration. This is clearly particularly important when the person doing the involvement is also in a position of power with regard to service provision for the person being involved. People may be concerned that their mental health is being assessed throughout the process and may be concerned that any criticism is seen as a symptom of mental illness, or of lacking insight. They may also be worried about being treated less well or even having services removed as a result of any criticism. Furthermore, some people who have either received very little support, or have previously received very poor support, may be so grateful for the current provision that they feel disinclined to be critical at all, even when the desire for service user feedback is completely genuine (Middleton et al., 2004, Linhorst et al., 2002). In addition there is the perfectly normal human desire to please, which could also have an impact on what someone is prepared to contribute to involvement process as an individual.

Most of these issues are equally true in a group setting, although if the group is made entirely of mental health service users, or if the group takes place in an environment of their choosing, people may feel more able to be critical. There are, however, additional power issues that can occur in group settings. If the groups involve professionals as well as mental health service users, it is quite possible that the power issues that occur on an individual basis could be magnified. It is also possible that professionals may take on the role of speaking on behalf of people they work with. Even in groups made up solely of mental health service users, there may well be power imbalances (actual or perceived). These can result from gender, race, class, diagnosis, disability or prior experience of discrimination. It is also possible that some people may be more reluctant to contribute their views, where they are at odds with those either already expressed, or that seem to be the majority view. Some people may simply be more reluctant to express their views in a group setting. One challenge when establishing a group is the balance between involving a greater number of people to try and broaden the range of views expressed; and keeping the numbers constrained so that some people do not feel intimidated by the size of the meeting.

By using current or former mental health service users as researchers or group facilitators, some of these power issues can be mitigated: the service user facilitator is unlikely to be in a position of power over members of the group (beyond the group facilitation), nor are they likely to be service gate-keepers or deliverers of coercive treatments (there are some exceptions, for example where peer support workers are paid employees of a trust, for example). The nature of the role of facilitation does, however, mean that some power imbalance is inevitable.

Other power issues

One of the most important power issues around service user involvement is that of who is involved. The issue of presence forms one of the key tenets of the 4PI framework (Faulkner, 2013). This is particularly important when involvement moves from a local level to a national level. Some of the most significant blocks to effective mental health service user involvement occur as a result of preventing people from being present for involvement mechanisms. It is particularly important, therefore, that the development of standards for mental health services involvement ensures the broadest possible presence in the process.

There are always compromises to be reached around presence, particularly when resources are limited. Under these circumstances monitoring, who is and who is not present becomes an important safeguard against involvement bias.

Mechanisms that involve travel can easily exclude people by virtue of cost, even if expenses are reimbursed people may be out of pocket or unable to afford upfront costs. Time constraints can

particularly disadvantage those who have caring responsibilities and those living in rural areas. Even the choice of time, will have an impact on who is able to attend: for example times that suit parents with school age children are unlikely to suit those in paid employment or vice versa.

3.3 EFFECTIVE MENTAL HEALTH SERVICE USER INVOLVEMENT

My research is about effective service user involvement. I have chosen the concept of "effective" mental health service user involvement to emphasise the range of approaches that are referred to as involvement and to try to narrow down my work to those that have a positive impact, with the assessment of impact forming part of the indication of effectiveness. This will include some of the challenges of the different people and settings, an analysis of a range of existing approaches and gaps, some of the common blocks to service user involvement and some of the evidence of the impact of involvement.

3.3.1 Moving towards measurement

Attempts to measure involvement in mental health services date back to the 1990s. Kent and Read (1998) described the development of the consumer participation questionnaire designed to measure consumer involvement in the planning, management and evaluation of mental health services and the attitudes of mental health workers towards consumer participation. Rogers et al. (1997) described the development of a consumer constructed scale to measure empowerment amongst mental health service users.

Despite this work, the idea of measuring involvement has, as recently as 2008, been described as an area that is not well-developed; although a number of instruments were found there was little evidence of their effectiveness or use (Stringer et al., 2008).

3.3.2 Standards for involvement

Qualitative assessment of the experience is in widespread use, particularly in service evaluation. Quantitative work, particularly measurements and targets, have become much more widespread in health, and mental health, but these tend to focus on symptoms or clinical outcomes, rather than service user defined outcomes (Perry and Gilbody, 2009, Shumway et al., 2003). Standards provide a good bridge between qualitative analysis of experience of mental health services or mental health service user involvement and quantitative measurements and targets. Many local services have introduced standards for service user involvement and Diamond et al. (2003) describe an audit approach to examining the implementation of local standards, identify areas for improvement in service user involvement, and consider its impact. Creating national standards offers the opportunity to assess the quality and impact of mental health service user involvement between areas and over time.

Since my initial development of a framework for measuring service user involvement using indicators as part of a self-assessment or audit approach (Crepaz-Keay, 2012) , the National Survivor User Network (NSUN, England's national mental health service user network) has started its National Improvement Partnership (NIP) project 'Involvement for Influence – Influence for Improvement'.

The purpose of NSUN's NIP project 'Involvement for Influence – Influence for Improvement' is to develop national standards for the involvement of service users and carers in mental health and social care services, and establish a national infrastructure for involvement (Faulkner, 2013). I have described this project and how my research relates to it in chapters 1 and 2.

3.4 SEEKING CONSENSUS – CHOICE OF TECHNIQUE

The purpose of this study is to acquire a set of indicators of effective mental health service user involvement which has a basis in literature, is applicable in the real world, and, most importantly, has come from service users rather than academics or practitioners.

In order to obtain objective indicators of effective service user involvement, there needs to be consensus amongst mental health service users about what constitutes effective involvement. A large number of potential indicators were drawn from the literature (the process is described in more detail in chapter 4) all of which had been used in, or recommended for, a real-world setting; they had been regarded as of value. These indicators came from a wide range of sources, but were not necessarily generated by mental health service users. Very few mental health service users have published in peer-reviewed journals and the degree of service user involvement in published works is not always apparent. It is important therefore, that this process is entirely owned by mental health service users, and the process used is, in itself, effective in its involvement.

3.4.1 Methodological techniques considered

I considered a number of alternative mechanisms for engaging people in this study. Below is a list of the techniques considered, with a brief description of their advantages and disadvantages with respect to this particular study.

Individual interviews

Individual interviews are widely used as part of service user involvement, often as part of a user satisfaction exercise. Interviews are generally structured or semi-structured, giving a balance of direction from the interviewer with space for the interviewee to add their own themes or priorities. This technique usually requires recording, transcription and thematic analysis. It offers no interaction between research participants. Interviews can be conducted remotely.

For the purposes of this study, individual interviews would have offered insufficient interaction amongst experts to be appropriate and the resources required to reach significant numbers would have been beyond those available for the research. The collection and analysis would have been entirely my own and although the methods, and even the (anonymised) data could have been made available for inspection, broader involvement in analysis would not have occurred and objective consensus would have been hard to demonstrate.

Focus groups

Focus groups are widely used in mental health service user involvement and are used in other parts of the 4PI framework development (Faulkner, 2013). Focus groups enable interaction between participants but require strong facilitation, reporting and usually transcription and thematic analysis. They also require participants to be able to travel to the groups and are fixed in time and space. Focus groups do not always elicit the most constructive contributions from people who are uncomfortable in group settings and group behaviour can reinforce power relationships.

Although some of the disadvantages of group dynamics can be addressed through skilful facilitation, the cost of addressing access issues to engage people from across England remained beyond the resources available for this study.

Nominal Group Technique

Nominal group technique (NGT) is a structured evaluative methodology in which group interactions are strictly controlled by the leader. This technique was originally developed as a way of facilitating group or team decision making through seeking consensus. Although NGT eliminates many of the

power issues associated with group dynamics by using a highly structured approach to group interaction (Delbecq et al., 1975). It has been successfully used for service user involvement (Perry and Linsley, 2006).

Although NGT has proven to be effective at reaching consensus, whilst addressing power relationship issues, it requires a physical meeting and requires more than one person to facilitate therefore would have required more resources than those available to ensure diverse involvement.

Surveys and questionnaires

A completely different alternative to any kind of physical meeting would be to use questionnaires or surveys. Surveys can reach far greater numbers of people than physical meetings and do so at considerably lower costs. They offer many advantages including: individualised anonymous responses that are not subject to peer pressure or researcher pressure; no travel or direct expenditure required from participants; and people can complete surveys or questionnaires in their own time at their own pace. Survey respondents are usually selected either randomly or purposively as representative of a larger population and are either one-off events or lead to follow-up work with a subset of the original participants. Although the survey has many strengths as a tool, for this research, I wanted to explore expert opinion and identify consensus rather than reflect mass opinion, making Delphi a more suitable choice.

3.4.2 Delphi process

The Delphi process is an iterative survey based approach design to help experts reach consensus. The process enables people to contribute remotely and, within the time constraints of the study, at a time of their choosing. It is possible to reach a large number of people across different countries if required, at relatively little cost. The questions are described in advance but space can be made available for contributions from participants.

The key differences between traditional surveys or questionnaires as an approach and the Delphi process are that participants are recruited as experts, rather than randomly or purposively selected to represent a broader population; and the process is iterative enabling mediated, staged interaction between participants.

The Delphi method was developed by the RAND Corporation in the 1950s. It was designed to seek consensus amongst experts primarily for forecasting purposes, initially on defence related matters (de Meyrick, 2003). Delphi has continued to develop since and has been widely used for a range of purposes and in many fields, it has been used for over 1000 published studies in the health field alone (McKenna, 1994). The three basic characteristics of the Delphi process, according to de Meyrick (2003), are:

1. Repeated individual questioning of the experts;
2. Avoiding direct communication between the experts (anonymity); and
3. Interspersed controlled opinion feedback.

As the purpose of this study is to seek expert consensus rather than gauge broader opinion, the Delphi process seems to be more appropriate, and I have given more detail about the Delphi process later in this chapter.

The techniques reviewed and considered, with their advantages and disadvantages, are summarised in table 3.1, below.

Table 3.1 – Characteristics of research techniques

	Resources required	**Advantages**	**Disadvantages**
Individual interviews	Meeting room or telephone, scribe or recorder, travel may be necessary	Enables detailed exploration, reduces impact of group dynamics	Resource intensive for significant numbers, analysis is time consuming, no interaction between participants
Focus Groups	Meeting room, scribe or recorder, facilitator, travel required	Benefits of group thinking, highly interactive	Requires people to travel, group dynamics may be unhelpful, analysis is time consuming
Nominal Group Technique	Meeting room, scribe or recorder, facilitator, travel required	Interactive, but manages group dynamics	Complicated facilitation, requires people to travel
Written surveys	Survey designed, resources for collecting and collating if volume is high, online access if used	Can reach high numbers at low cost, no physical meeting required	No interaction with researcher or detailed exploration
Delphi Process	Survey design, online access if used	Allows controlled interaction through iterations, no physical meeting required	Experts need careful selection, can be repetitive, duration not clear at outset

3.4.3 Advantages of Delphi

The Delphi method has been chosen for this particular study because it is designed to help experts reach consensus on complicated issues. The Delphi method is a mechanism well-suited to addressing many of the key power imbalance issues identified above. I have also taken into consideration the range of mechanisms used in other parts of the 4PI framework to try and enhance involvement in standards development by using a mechanism not used elsewhere in the 4PI development process.

The Delphi method seeks to draw on the advantages offered by consulting groups of people, whilst mitigating the power imbalances identified as an inherent part of group dynamics. It also seeks to reduce the power imbalance between the person being involved and the researcher that occurs in individual involvement.

- People have been through an application process and been selected against predetermined criteria. This helps reinforce their self-esteem and elevates their status from mental health service user to expert contributor.

- In this particular study, people are paid for their involvement, which directly values their opinion.
- People are explicitly asked to express their own opinion and do so completely independently of others involved in the process.
- People are generally not physically present with other participants, or with the researcher. This reduces social pressure to either please the researcher or conform to the norms of others involved.
- People do not know the names, roles, or status of other panel members, and therefore cannot place themselves or be placed by others in a power hierarchy.
- There is no direct cost to take part, so no one is excluded on the basis that they have to contribute financially in advance and claim back expenses.
- People can complete the process at a time that suits them, enabling them to fit this in with existing or potential commitments.

Whilst the process of each Delphi round is individual, the analysis between rounds enables participants to see how other people have responded, but without knowing who precisely has contributed what. The presentation of analysis between rounds enables people to focus on where consensus has not been reached. It also provides a degree of transparency to enable participants to feel part of a broader process, but without feeling pressured to conform.

There are also significant advantages for the researcher. The absence of physical meeting can significantly reduce the costs of the study. The administrative effort, time and cost involved in arranging venue, refreshments and travel is eliminated. There is very little additional cost associated with involving more people, so the panel size can be chosen on the basis of utility rather than cost. The researcher also has the same freedom from geographic or temporal constraints.

The selection of expert panellists is not significantly different from recruiting participants for any kind of group discussion. These experts are people who are experts in mental health service user involvement. All of the experts are people who have direct personal experience of using mental health services, and this is an important principle for this study.

3.4.4 Potential pitfalls of Delphi

Linstone and Turoff (1975) identify a checklist of pitfalls to help guide the construction of Delphi studies. Though some of these are specific to forecasting, others are entirely relevant to this study. The relevant pitfalls (numbers taken from Linstone's original list) are (4) illusory expertise, (5) sloppy execution, (7) overselling and (8) deception.

Illusory expertise

The phrase "expert by experience" has become common in the field of mental health service user involvement (from as early as Faulkner, 1998, but becoming more common recently, for example, Reichel, 2011, Lakeman, 2010, Bergmans et al., 2009). The purposes of the Delphi panel experience of using mental health services is not, in itself, expertise. In order to assure genuine expertise panel members were recruited against a role description and asked to submit details of their experience in service user involvement. This process is outlined in more detail in chapter 4.

Sloppy execution

The pitfalls around execution identified are poor selection of panellists, poorly formed questions or statements, problems with analysis, poor completion by panellists. Panel selection and question formation are covered in detail elsewhere in this report; because of the nature of this particular study, there are few precedents to guide analysis. The analysis is therefore being made as

transparent as possible so that others can judge the analysis and conclusions for themselves; poor completion by panellists is difficult to control for, but careful analysis of text comments submitted by panellists suggests that they have taken the tasks seriously.

Overselling
This pitfall concerns the use of Delphi itself in situations where it may not be the appropriate tool, or on making a simplistic correlation between the number of panellists and the quality of the output. To some extent these are judgement calls and provided the rationale for use of Delphi and panel size are adequately explained this potential pitfall does not seem to be a major problem in this study.

Deception
The Delphi process is not immune to manipulation or misuse. There is a risk that the anonymity inherent in the process may encourage people to make untrue statements or judgements in a way that they would not were their identities to be known. It is also possible that someone running a Delphi process could deliberately manipulate the analysis for their own ends without anyone being able to judge if this is the case. In this study, all responses and subsequent analysis are completely transparent, though anonymous, to any participant, once they have completed each round. This should provide assurance that judgements made are genuine and the analysis is based on the actual expert opinions submitted.

3.4.5 Other potential problems with Delphi
A number of criticisms of the Delphi methodology occur in the literature, and highlighted by Loo (2002), particularly around sample design and reliability and validity. The sample design issues come from comparing the sampling approach for constructing a Delphi panel with traditional sampling methods relying on larger number size and random selection. The Delphi process, by contrast, relies on a smaller number of people selected against criteria rather than randomly. Reliability and validity issues will vary from study to study, measures taken to ensure validity and reliability within this study are explored in more detail later in this chapter when the Delphi study design is described.

3.4.6 Delphi online
Although the Delphi process is well described (see Delbecq et al., 1975), there are a number of ways to administer it. I have chosen to use an online Delphi tool (Armstrong, 2003).

Advantages of online Delphi
The Delphi Decision Aid website is free to use both as an administrator and as a panel member. The site actively supports the process of setting up and administering an entire Delphi study. This includes question design, expert selection, process monitoring and analysis. The site also anonymises individual participants to reduce the risk of researcher bias in analysis.

The site tracks participants' progress and can automatically issue reminders to people who have yet to complete each stage of the process. There is no limit to the number of questions in any particular round. There is no limit to the number of rounds. There is no limit to the number of experts. It only requires Delphi panellists to have Internet access.

Limitations of online Delphi
Although the number of questions is not limited, questions are limited to one of four types: text, which allows a free text answer; open-ended, which allows a numeric answer; scaled, which allows an answer within a range (with or without intervals); or ranked, which requires people to order a number of statements.

The level of analysis available when using this site is limited. It is not possible to access the data entered by each participant. In the case of ranking type questions, the data available are restricted to each items' average rank, best rank, worst rank, and a number of times ranked first. This restricts the level of analysis possible on completion of the study.

It is clearly necessary that panel members have access to the Internet; it is inevitable that this requirement will exclude some people.

3.5 On consensus

One of the key advantages of using the Delphi process for this study is its strong association with consensus (Mullen, 2003). It is important, however, to consider what I mean by consensus in the context of this work. Although pure consensus would involve everyone agreeing, in the real world a more pragmatic view is taken. Consensus levels are often set, these will depend on the nature of measurements used for scoring in each round. Where options are scaled or ranked, statistical tests can be applied and consensus levels set at statistically calculated points. It is possible that some opinion may be masked by statistical analysis and over reliance (Rudy, 1996, cited in Mullen, 2003), and that some consensus measures, if too narrow, do not take full advantage of the information available (Scheibe et al., 1975, cited in Mullen, 2003). There is also concern expressed that people who do not agree with the general views expressed in the first round may not contribute to subsequent rounds, hence reducing the diversity of the panel and reducing the validity of the consensus, so observing attrition rates between rounds is important (Mullen, 2003).

Where concepts are more complicated, multimodal consensus may occur (Scheibe et al., 1975, cited in de Meyrick, 2003) with clusters of rankings, where this occurs, sticking rigidly to numeric values or fixed percentiles can ignore consensus.

In order to address these concerns, and in order to make use of all the information provided by the online Delphi tool chosen, I have sought consensus primarily based on average ranks and I have set fixed consensus levels in advance: consensus on a good indicator being set at those above the 10^{th} percentile and consensus for elimination as not a good indicator being set as those below the 67^{th} percentile. As the ultimate aim of my study is to promote the most effective mental health service user involvement, as judged by my panel of experts in involvement, I have set a higher level of consensus for the best ranking indicators (top 10%) than for those eliminated (bottom 33%).

I also looked at clusters of indicators with similar averages, and I used the number of times any indicator was ranked first to avoid false consensus where the distribution of ranks is multimodal. I was also guided by comments from panellists where decisions on consensus using quantative information alone were marginal.

3.6 Designing and conducting the Delphi study

On balance, I concluded that the advantages the Delphi Decision Aid site offered outweighed its limitations and chose to proceed on this basis. I designed and conducted the Delphi study using the four stages identified by Loo (2002): problem definition, panel selection, determining the panel size and conducting the Delphi rounds.

3.6.1 Problem definition

The problem definition for this study is to reach consensus on indicators of effective mental health service user involvement, so that they can contribute to the process of developing national standards. In particular, to be able to use indicators to sort mental health service user involvement from basic to excellent.

Question type

As stated earlier, one of the limitations of the Delphi Decision Aid site is the limited number of question types. Of the four available (as outlined above), two types seemed appropriate: scaled and ranked. In order to assess which of these question types was most appropriate, I ran a trial process with each involving people from the NIP team; this trial is described in more detail in chapter 4.

As a result of trying the different question types, I decided to use ranking. Each question consisted of a number of statements describing mental health service user involvement (initially drawn from the literature review, with additions from expert suggestions for the second round). Panel members were asked to rank the statements with rank of first representing the best example of service user involvement.

3.6.2 Panel selection

For the purposes of this study, an expert was defined as someone who met the following criteria:

- Personal experience of using mental health services
- A track record of involvement and influence, improvement and impact
- Innovative ideas about involvement, influencing, improvement and impact
- An in-depth understanding of the current involvement experiences and challenges faced by the diverse range of people with mental health problems and the family and friends who provide care and support to them
- An ability to draw on your own experience and that of others who use services and/or their family and friends to inform involvement policy and service development
- Experience of working on a formal committee at local or national level, e.g. LINKS, NHS Trust Board, Service user/carer group, School Governors, Private sector business, charity, community, cultural or faith groups
- Experience of working with organisations at a local or national level and an understanding of how involvement could be developed strategically
- An interest in extending the philosophy of process, presence, purpose and impact (PPPI) in service user involvement

The recruitment process is described in more detail in chapter 4.

3.6.3 Determining the panel size

Delphi panel sizes vary over a considerable range, but in a review of a number of studies using Delphi, Mullen (2003) identifies typical panel sizes from 8 to 12 up to hundreds. Studies looking at a relatively homogenous group of participants tend to sit at the lower end, for example, a study of mental health intensive case managers in the United Kingdom had only eight participants (Fiander and Burns, 2000). International studies, where panellists are far more diverse, can be considerably bigger; for example, a study seeking first aid recommendations for psychosis had an international panel of 157 (Langlands et al., 2008). I sought studies that were relatively recent and had mental health service user panels as an appropriate comparator for panel size. I found a recent study into user defined outcomes in mental health had a panel of 26 (Perry and Gilbody, 2009); another, into adolescent mental health first aid, had a panel of 36 “youth mental health consumer advocates”

(Ross et al., 2012). With these studies in mind, I initially aimed to recruit a panel of 20 to 30 people. This panel size is consistent with recommended practice (Loo, 2002) and should allow for a degree of diversity, but remain manageable. The actual panel used was a little larger but within the range suggested by similar studies. Full details of the recruitment process and details of the final panel are given in chapter 4.

3.6.4 Conducting the Delphi rounds

Developing the questions

The questions for the first round of the Delphi study were developed in a way consistent with good survey design, as suggested by Loo (2002). The subject areas were drawn from a review of the literature on mental health service user involvement.

In order to develop a manageable framework for indicators I have adopted a three level stratification of involvement: individual, operational and strategic. The use of these levels is widely acknowledged (see, for example, Perkins and Goddard, 2004) and will also make the indicators more useful and easier to analyse and act upon in a service setting. The key terms used for each level are listed below:

- Individual
  Terms which cover the principle of involvement at an individual level: empowerment, participation, and personalisation.
  Terms referring to particular types of involvement at an individual level: self-management, crisis cards, care planning, and advanced directives.
- Operational
  Terms chosen for operational level were: training, education, peer support, monitoring, recruitment, and service provision.
- Strategic
  Terms chosen for strategic level were: planning, commissioning, governance, service reorganisations, and policy.

All the initial indicators came from the literature review. The following criteria were used to identify potential indicators:

- Some tangible form of service user involvement in a real-world setting was described, some of these were recommendations or suggestions, rather than current activity.
- The involvement described was seen as a useful, either by the author of the paper, or by service users or providers, or some other stakeholder.
- The involvement described was possible to replicate.

The process of identifying indicators and developing the questions is covered in more detail in chapters 4 and 5.

First round

Indicators identified from the literature were stated as examples of mental health service user involvement. They were grouped into three levels of involvement identified above. The operational level was subdivided into five subcategories: training, support and payment for service users to be involved; involvement in staff recruitment and training; involvement in delivering and evaluating services; involvement in delivering and evaluating services; and, measurable impact.

The first round also allowed space for comments and suggestions for additional indicators for subsequent rounds.

The aim for this round was to identify consensus on statements that identified the most effective and the least effective examples of mental health service user involvement.

The first round also included extensive guidance for panel members. It is likely that many, if not most, panel members will be new to, or relatively inexperienced in the Delphi technique. With this in mind the first round was supported by a range of materials including: a two page instruction note and a full list of statements for ranking. The Instructions explained the Delphi process in general; details specific to this study, including timescales; the purpose of the study; guidance on how to answer the first round, including a worked example; how to make comments and give feedback for subsequent rounds; and, what people could do in the event of difficulties (technical or otherwise). A copy of these notes are attached as appendix a, the full list of examples presented to the panel in the first round is attached as appendix b.

The first round was analysed using frequency with which a statement ranked number one, and the average ranking a statement received from the panel. Consensus was deemed to be reached where either a significant number of people ranked an item as first, or where the average rank was significantly high or low, compared to other items. Comments received were imported into NVivo 10 for windows and analysed for themes. Where there were comments related to either rankings or suggestions for additional indicators, they were taken into account for the second round.

Comments on process, or other technical issues, were analysed separately. Where indicated, process or technical changes, or additional instructions, were provided for the second round.

Second round

The second round of the study included statements from the first round for which no consensus was reached that they were either the most or least effective examples mental health service user involvement. This round also included indicators identified by panel members in the first round. The aim of this round was to identify consensus on the remaining, and additional, statements; and to judge whether a third and subsequent rounds would offer significant benefit in seeking overall consensus.

The same question structure as the first round was used for the second round. Once again, the panel was given a full list of statements for ranking, in this case with additional suggestions from the panel highlighted. In addition, the panel was given a feedback summary from the first round, and details of how to access a more complete summary online, so that they were able to see how statements were ranked at the panel as a whole and where consensus had been reached. A copy of this note is attached as appendix c, the full list of examples presented to the panel in the second round is attached as appendix d.

The Second round was analysed as the first. Consensus was deemed to be reached where either a significant number of people ranked an item as first, or where the average rank was significantly high or low, compared to other items.

After the second round.

On completion of the second round, a decision would be made regarding the necessity or benefit of any subsequent rounds. This judgement would be taken on the basis of whether sufficient consensus has been reached, results were repetitive, or an impasse is reached (Loo, 2002).

3.7 CONCLUSION

This chapter has described the methodology and methods chosen for my research. I have explored the importance of power relationships in mental health service user involvement and explain how I have addressed them in order to make this research emancipatory. I have explained some of the specific methods I considered and why I chose the Delphi study from those available. I have explained the concept of consensus and the way I have chosen to apply it. I have provided a detailed description of the way I have then applied the Delphi process to seek consensus on indicators of effective involvement.

The next chapter will describe how I have applied these methods in practice.

4 RESEARCH ACTIVITY

4.1 INTRODUCTION

This chapter explains the work done to refine the long list of potential indicators outlined in the previous chapter to a list on which there is expert consensus, using the resources available to me. This includes a detailed description of the way I implemented the Delphi process including defining the questions, the Delphi panel members, the question types chosen and the conduct of the Delphi process online. This chapter also includes a complete list of the potential indicators set before the panel for the first round, the activity between rounds and the questions that went into the second round.

4.2 RESOURCES AVAILABLE

One of the advantages of this study becoming part of the NSUN/NIP project was that this gave me access to additional resources above and beyond those available from within the Mental Health Foundation. The project is funded by the Department of Health under its strategic partnership fund. Some of my time spent on this research was covered by this budget.

4.2.1 Networks

The Mental Health Foundation has a strong and active network of people with an interest in mental health policy. This policy panel has a membership of over 500, many of whom have direct personal experience of using mental health services. NSUN has a service user membership of 3,000 individuals and 500 groups.

4.2.2 Financial resources

In addition to staff and access to networks NSUN provided a budget to pay Delphi panel members for their contribution. Other incidental costs were covered by the Mental Health Foundation.

4.3 DESIGNING AND CONDUCTING A DELPHI STUDY

Loo (2002) identifies four key planning and execution activities for a Delphi study:

1. problem definition;
2. panel selection;
3. determining the panel size; and
4. conducting the Delphi rounds.

4.4 PROBLEM DEFINITION

The key element of problem definition at this stage of the process was to develop statements or questions that could be put to the Delphi panel.

4.4.1 Choosing the question types

One of the limitations of the Delphi Decision Aid site is constraint of question types. Four types are available (as described in chapter 3). Of these, two types seemed appropriate: scaled and ranked. In order to assess which of these question types was most appropriate, I ran a trial process with each involving people from the NIP team, as a trial panel.

In the first trial, I used a scaled approach. I described a series of characteristics of effective mental health service user involvement, as described in the literature, and asked the trial panel to score them from 0 (basic) to 3 (excellent). I used a sample of six characteristics drawn from the literature, chosen to reflect a diverse range of potential indicator characteristics and 6 people responded to this trial.

For the second trial, I used ranking. I drew a series of examples of effective mental health service user involvement from the literature, and asked the trial panel to place them in order from first to last, with first place going to the most effective and last place going to the least effective.

Although the scaled approach appeared initially to be simpler, reviewing the trial highlighted two distinct difficulties. The first difficulty was drawing the characteristics of effective mental health service user involvement from the literature. Most papers were not written with the characteristics explicitly stated, and therefore the statements I constructed relied too much on my interpretation. The second difficulty was that although scoring 0 to 3 was relatively simple, people tended to score at the extremes the scale, making it difficult to distinguish between characteristics. The main difficulty with the ranked approach was reported difficulty in ordering statements that could be quite different. No other difficulties were reported or observed during the trial.

As a result of this trial, I decided to use the ranked approach. The most significant advantage was the ability to draw examples of effective mental health service user involvement directly from published literature without having to interpret or distil characteristics, and in the distillation process lose or misinterpret the essence of what was being described. Each question consists of a number of statements describing mental health service user involvement (initially drawn from the literature review, with additions from expert suggestions for the second round). Panel members were asked to rank the statements with rank of first representing the best example of service user involvement. A detailed description of how the statements were drawn from the literature is set out below in the section on conducting the Delphi rounds.

4.5 PANEL SELECTION

4.5.1 Role description and person specification

As previously noted, it is important that the Delphi panel members have sufficient expertise to ensure that the results of the panel are valid and reliable. With this in mind, I developed a role description and person specification, against which potential panel members could be assessed. This was circulated for comments from the NSUN National Involvement Partnership team and amended in light of comments received. The final version is attached as appendix e.

4.5.2 Finding potential panellists

The role description was circulated to the Mental Health Foundation's policy panel and the NSUN membership. All circulation took place via digital means. This clearly meant its reach was limited to people with internet access; this may have excluded some people, but given that the study was to be completed online, it did not seem unreasonable to use the internet as the primary dissemination mechanism. A number of people passed the role description onto other groups or networks that they had connections with.

4.5.3 Selecting panellists

Following the initial circulation of the role description, 55 people expressed interest in the Delphi panel and further information was sent to them. People were asked to outline their experience of

service user involvement, they were also asked to complete a diversity monitoring form. 40 people completed the application process of whom two were carers rather than people with direct personal experience of using mental health services.

I reviewed the applications of the 38 mental health service users who submitted applications. The applications were checked against the role description to ensure that they had the experience necessary to be considered experts for the purpose of this Delphi study.

4.5.4 The Delphi panel

Involvement experience

I divided panel members' experience of mental health service user involvement into the three levels previously described: individual, operational and strategic. Every panel member had to have experience of involvement at one or more of those levels in order to qualify as a panel expert. Six people identified expertise at only one of the three levels, 15 identified expertise at two levels, and 15 at all three levels. 20 people had expertise in involvement at an individual level, 34 at an operational level, and 27 at a strategic level. What follows is a summary of mental health service user involvement experience as expressed through the application process; further experience and expertise was expressed throughout the Delphi study, and this is reported in later chapters.

Individual level

Of the 20 people who identified expertise in involvement at an individual level, 8 panel members had been members of self-help groups and a number of them had set up such groups. Some people identified this as a starting point for their involvement at other levels. Seven people mentioned structured self-management, including one panel member who helped develop one of the UK's first self-management interventions in mental health. When talking about self-help and self-management, people talked about the importance of sharing skills, peer support and social support. Other terms were used to describe individual involvement: self-advocacy, self-defined plans, personal empowerment and self-directed support. Several people mentioned actively seeking more holistic approaches to their mental health support as alternative or complementary to their statutory provision. The use of advocacy helped a number of people take more control over their own care.

Every panel member who was actively involved at an individual level was also involved at least one further level.

Operational level

Involvement at an operational Level was the most common level of involvement amongst members of the panel. This is consistent with other findings of this study suggesting involvement at an operational level is the most common form of involvement.

Involvement in the recruitment, training or education of staff was widespread with 11 panel members involved. This involvement included being a part of the recruitment panel, developing curricula for professional training, delivering training both within educational settings and the service settings. Fifteen panel members explicitly referred to training or consultancy as their primary or significant occupation.

Another significant group of panel members was those who had set up or were currently delivering services. Four people described their involvement in setting up or developing services and eight were currently employed delivering services. Two people had developed information for service users designed to improve their ability to make informed choices in services. It is quite common for

services to have a service user reference panel or advisory group, eight of the panel members were or had been members of such a group. Some people reported involvement in specific consultation exercises for example, reviews of benefits guidance.

Strategic level

The panel members had considerable experience of being involved at a strategic level. In the statutory sector, the most widespread involvement was board membership; seven panel members had sat on the boards of NHS trusts, partnership trusts or other provider trusts. In addition, two people were members of specific clinical governance groups.

Four people were involved in commissioning services, as part of a tendering process, or developing contract specifications and assessment criteria.

Statutory mechanisms for patient and public involvement (PPI) in England have developed significantly over the last 10 years. These have been designed specifically to engage patients and members of the public in developing future services based on their experience of current ones; all of these mechanisms work across the whole of the health (and sometimes social care) field and are not exclusive to mental health, but most have made a particular effort to get people from a mental health service use or caring background involved. Community Health Councils (CHCs) were replaced by PPI fora; which in turn were replaced by Local Involvement Networks (LINks); that have now become Healthwatch. Six panel members have been involved in at least one of these mechanisms, several of them being involved in more than one of these iterations over time.

The National Institute for Health and Care Excellence (NICE) produces guidance to support healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money. Two of the panel members have been actively involved in developing NICE guidance, including guidance on antenatal and postnatal mental health.

The most common strategic role taken on by panel members was trustee of a national or local mental health charity; 10 people perform this function. These charities ranged from very large national service providing charities to small local campaign groups; some people held both national and local trustee responsibilities.

Involvement across levels

There is not always a clear distinction between operational and strategic activity. Research for example, can clearly be about both what is happening now and what should happen in the future. Involvement in research, regulators or professional bodies clearly has elements of both operational and strategic, involvement. Eight panel members were involved in research groups or research project advisory groups. Eight people had been involved with regulators or professional bodies including the Care Quality Commission or its predecessors, the Royal College of Psychiatrists, and the Nursing and Midwifery Council.

Geographic spread

The panel had been actively involved in every region of England, though only 28 members identified their region. Table 4.1, below, gives a more detailed distribution of panel members, listing the number of people by region.

Table 4.1

Region of England	Panel members	%
North West	3	11%
North East	1	4%
Yorkshire and Humber	3	11%
West Midlands	6	21%
East Midlands	3	11%
East	6	21%
South West	2	7%
South East	1	4%
London	3	11%

Diversity

All applicants were asked to complete a diversity monitoring form (attached as appendix f). This was done to help ensure I understood the diversity of the panel, and so that I could actively engage people from any groups that were significantly underrepresented. Completion of the diversity monitoring form was optional, nobody was excluded from consideration for the panel if they chose not to complete the form. Thirty people completed and submitted the forms. I have discussed the diversity of the panel in more detail in chapter 6.

Gender has an impact on mental health service user involvement experience (see, for example, Barnes et al., 2006). The Delphi panel had a reasonable balance of male and female members, the details are shown in table 4.2, below.

Table 4.2

Gender	Panel members	%
Male	13	43%
Female	17	57%

The mental health field has a large number of variations both qualitative and quantitative on the basis of the ethnic origin of the service user (see, for example, Rosenfield, 2012, Seebohm, 2010, Desai, 2003). Although there is not an overrepresentation of white English people on the panel (the proportion of the panel was 63% compared with the proportion of the English population at the time of the 2011 Census which was 83% (ONS, 2011)), the absence of African and Caribbean panel members is a significant concern as this particular group have been systematically disadvantaged within psychiatry (a summary of evidence is cited in Desai, 2003). Possible reasons for this, along

with a discussion of its potential implications, can be found in chapter 6. The full breakdown is shown in table 4.3, below alongside the equivalent percentage for the population of England with the most recent official information available.

Table 4.3

Ethnicity	Panel members	Panel %	Population % (2011 Census)
White English	19	63%	82.8%
White Irish	2	7%	1.1%
White, other	3	10%	3.6%
Bangladeshi	2	7%	0.7%
Indian	3	10%	2.7%
Pakistani	1	3%	1.9%
Black British, Black African, Black Caribbean, Black other	0	0%	2.9%

Different ages will have experienced different service patterns, and different approaches and attitudes to involvement. For example, prior to the 1983 Mental Health Act, and the subsequent deinstitutionalisation, most people with a diagnosis of schizophrenia, personality disorders, and a significant number of people with bipolar disorder diagnosis would have experienced long periods of detention; whereas people with similar diagnoses experiencing services since 2000 are likely to have received most of their services in community settings. Attitudes towards mental health service user involvement have improved significantly over the last 30 years, so many of the examples of involvement quoted throughout this report would be seen as relatively new to older panel members, but seen as part and parcel of modern services by some of the younger panel members.

The Delphi panel has a good range of ages, which should allow the panel to reflect on significant cultural changes that have occurred over time. The full breakdown is given below in table 4.4.

Table 4.4

Age	Panel members	%
26-35	8	27%
36-45	8	27%
46-55	5	17%
56-65	4	13%
66-75	5	17%

Sexuality is an important aspect of diversity. People of non-heterosexual orientation report elevated levels of mental health problems and service usage, and their experience of discrimination may increase distress within and outwith mental health services (Chakraborty et al., 2011). At 23%, the non-heterosexual proportion of the panel is significantly higher than England as a whole, and should

therefore ensure a good degree of diversity is reflected. The full breakdown is shown in table 4.5, below.

Table 4.5

Sexuality	Panel members	%
Heterosexual	23	77%
Gay	2	7%
Lesbian	1	3%
Bisexual	3	10%
Other	1	3%

4.6 DETERMINING THE PANEL SIZE

The application and selection process resulted in 38 people who met the criteria to be considered experts for the purposes of the panel. Although this number exceeded my initial expectation for a panel size, I could see no significant disadvantage in expanding the panel to allow everyone who met the requirements to become a panel member. A panel of 38 people remained close to the sizes identified from recent comparable studies (Ross et al., 2012, Perry and Gilbody, 2009).

NSUN agreed to my request to fund the expanded panel, and made payment available for all of 38 people. In practice, two of these people did not complete any part of the Delphi process and so the panel referred to for purposes of analysis consists of the 36 people who completed at least one question in either of the two rounds.

4.7 CONDUCTING THE DELPHI ROUNDS

4.7.1 Testing Delphi online

Having identified the online Delphi Decision Aid tool (Armstrong, 2003), I ran a test Delphi exercise to check for usability. I chose a small panel of five people whom I knew to have different degrees of technical ability, all of whom were regular Internet users. They used a variety of browsers and operating systems. This usability pilot took place before the testing of different question types. For the purposes of the usability pilot, I used a scaled approach and asked people to score examples of involvement from 1 to 5.

The usability pilot highlighted the following advantages: the site appeared to be easy to use and every participant managed to complete every question, with the option of additional comments from panel members if they wish to give any. The site analyses and reports responses clearly, including up-to-date status of question completion; and, it handles all administrative tasks easily, including generating invites, issuing reminders, anonymising responses and guiding panel members through the process.

The pilot also highlighted a number of disadvantages: the site does not offer a project overview at start of the round; it does not allow you to provide standard info that remains unchanged for all questions; and, you cannot reorder questions once entered. The first two issues were resolved by providing detailed information, the panel members as part of their instructions; the latter is a minor irritation that certainly made the final panel all time consuming to construct.

Some additional limitations of the site, particularly around analysis, became apparent once I started using a ranking approach; these limitations are set out in chapter 3.

4.7.2 First round

Instructions for panel

It was clear from both the usability pilot, and from the trials of different question types, that panel members would need explicit and unambiguous instructions in order to complete the process accurately and with minimal difficulty. The Instructions were circulated for comments to a small number of people from the NIP team. They explained the Delphi process in general; details specific to this study, including timescales; the purpose of the study; guidance on how to answer the first round, including a worked example; how to make comments and give feedback for subsequent rounds; and, what people could do in the event of difficulties (technical or otherwise). A copy of these notes are attached as appendix a.

Developing the questions

Once it became clear that the best approach to selecting indicators was to ask panel members to rank real world example of involvement, rather than to score characteristics, the next task was to set criteria to guide the selection of examples from the literature identified earlier. The following criteria were used to identify potential indicators:

- Some tangible form of service user involvement in a real-world setting was described, some of these were recommendations or suggestions, rather than current activity.
  The examples needed to be recognisable to the panel members. By using example that were either reported from actual settings or suggested by papers from research, it seemed likely that the panel would be able to identify them and compare them with each other.
- The involvement described was seen as a useful, either by the author of the paper, or by service users or providers, or some other stakeholder.
  To ensure effective involvement, it was important that the examples were thought to be effective. I took this to mean either that the author(s) of the paper believe or found them to be effective; or that they were reported to the author(s) as such.
- The involvement described was possible to replicate.
  It is one of the aims of this study to encourage the improvement of effective mental health service user involvement. To support this, it is import that the involvement examples can be replicated. There would be little point in identifying an activity as highly desirable if it were not possible to repeat it in other settings.

The questions in full

The following is the complete list of questions as they appear for Delphi round 1

Individual

The following are examples of how people are involved in their own care and treatment (involvement at an individual level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 14.

1. People using services identify their own needs
2. The service/treatment goals are set by service users
3. The service/treatment goals are life orientated rather than symptom orientated
4. The service/treatment goals are jointly set by professionals and service users
5. People have a choice of services/treatments
6. People have the positive and negative effects of treatments clearly explained
7. Service users are actively trained to achieve treatment goals
8. Professionals actively share responsibility and decision-making with service users
9. All discussions about services/treatments are in plain English
10. The service/treatment focuses on the service user's strengths and potential
11. Service user led self-help groups are promoted by the service
12. People are encouraged/trained to engage in self-management
13. People are actively encouraged to find their own sources of support
14. Mechanisms for advanced decision-making (for example advanced directives or crisis cards) are offered

Operational

The following are examples of how people are involved in how services are run (involvement at an operational level). This has been divided into 5 sub categories.

Training, support and payment for service users to be involved

This sub category is training and support for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 6.

1. People involved are supported to meet together regularly
2. The organisation has a policy on payment for involvement
3. Training is offered for people who get involved
4. People are offered payment for their time
5. People have their expenses paid at time of, or after, the involvement
6. People have their expenses paid in advance

Involvement in staff recruitment and training

This sub category is involvement in staff recruitment and training. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

1. Service users deliver training independently of professionals or other trainers
2. Service users deliver training in partnership with professionals
3. Service users contribute to a professionally led training session
4. Service users contribute to design the training curriculum
5. Service users contribute to the development of training
6. Service users are part of professional development assessment process
7. Service users contribute to staff job descriptions
8. Service users are involved in shortlisting candidates
9. At least one service user is part of an interview panel for all staff recruitment

Involvement in delivering and evaluating services

This sub category is involvement in delivering and evaluating services. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

1. Services provide clear information about medical treatments written by professional in clear language
2. Service users contribute to the production of official information
3. Service users are provided with information written by service users
4. Service user involvement is led by a service user in a paid role
5. Peer support is part of the service but led by professionals
6. Service has peer workers who are paid employees
7. Service users choose their peer support
8. The service addresses the physical health needs of service users
9. User focussed monitoring is in place

Mechanisms for involvement

This sub category is mechanisms for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

1. The service has a regular meeting that service users can attend to get involved
2. Decision-makers from services visit service users at service user led meetings
3. The service has an independent service user panel
4. Some of the service's operational meetings include one or two service users
5. Games based approaches to involvement are used
6. Meetings are structured to ensure equality of involvement for all participants
7. Online, social networks and other remote techniques are offered to enable involvement without physical presence
8. Story-telling and drama presented by service users is used as a way to present service user views
9. Service users engage in outreach work to ascertain views of other service users and report back

Measurable impact

This sub category is impact of involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 6.

1. Services demonstrate improved mental health outcomes linked to involvement
2. Services demonstrate improved health outcomes linked to involvement
3. Services demonstrate improved quality of life linked to involvement
4. Services demonstrate reduced discrimination linked to involvement
5. Barriers to involvement are identified and reported
6. Barriers to involvement are identified and overcome

Strategic

The following are examples of how people are involved in how services will be in the future (involvement at a strategic level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 11.

1. Service users attend the governing body
2. Several service users sit on the governing body
3. Service users review and report to the governing body
4. Service developments are clearly influenced by user focussed monitoring
5. Service users define the purpose and direction of the service
6. New services are jointly designed or co-produced by service users and professionals
7. Services demonstrate any changes linked to involvement
8. Service users are involved in the commissioning of services
9. Service users are involved in contract specification
10. Service user involvement is explicitly included as part of clinical governance
11. Service users are given the resources required to develop their own services

Note on the examples

At this stage it should be stated that the examples as put before the Delphi panel for the first round could not claim to be service user generated. They have been extracted from published literature which may or may not have included a degree of service user involvement. Where the level of involvement is known, this has been stated in the literature review.

The first round online

Once the questions were extracted from the literature, and set out on the Delphi Decision Aid site, the round went live and invitations were issued. I manually sent each panel member a set of instructions (as described above), and told them that they will shortly be receiving an invite issued by the Delphi Decision Aid site.

The automatic invite from the site included a direct link to a personalised page for each participant. There was also a link to a generic page where people could enter their email address and be taken to their personalised page. This would allow people to complete the round over several visits if they wished to.

The first round opened on 27 May 2013 and closed on 10 June. Reminders were issued on 1 June and 8 June to panel members who had not completed the round.

Technical problems encountered

When I opened the first round, technical problems occurred for a number of panel members. For one panel member, the link in the email invitation did not work at all, and they were unable to reach their personal page. I reissued the invitation twice but the revised link also failed. When used from my computer the link preformed as expected. I deleted and reinstalled the user account for the panel member but that did not resolve the problem. The panel member had an alternative email account so I set up an account using this address and the subsequent link worked correctly.

After three days, I received an email from one panel member asking when they would receive the invitation; as they should have received it three days prior, this was a matter of concern. I sent an email to all panel members who had not, according to the administrative logs, accessed the site to ask if they had received an invitation. Seven panel members reported not receiving the original invite; I asked them to check their spam/junk mail folders/filters and this accounted for five of the missing invitations. I reissued the remaining two invitations; one worked and one still failed to appear. I removed and reinstalled the account for this panel member and the new invitation worked correctly.

Completing the first round

All panel members received an email notifying them that the first round been completed. This email included a link that enabled all panel members to see the results of the first round. I also sent a note thanking panel members for their contribution to date.

4.7.3 Second round

Preparing the second round

Consensus was reached on 6 items for question 1, 3 items for question 2, 4 items for question 3, 3 items for question 4, 3 items for question 5, 2 items for question 6, and 4 items question 7. These items were removed the second round. Additional items suggested by panel members during round one were added. 3 items were added for question 1, 1 for question 4, 3 for question 5, 1 for question 7, and 1 for question 8. These new items were highlighted in the guidance issued for panel members for round 2. A detailed analysis of consensus reached is given in chapter 5.

The questions in full

The following is the complete list of questions as they appear for Delphi round 2, with the additions **highlighted thus.**

Individual

The following are examples of how people are involved in their own care and treatment (involvement at an individual level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 11.

1. The service/treatment goals are set by service users
2. The service/treatment goals are life orientated rather than symptom orientated
3. The service/treatment goals are jointly set by professionals and service users
4. People have the positive and negative effects of treatments clearly explained
5. Professionals actively share responsibility and decision-making with service users
6. The service/treatment focuses on the service user's strengths and potential
7. Service user led self-help groups are promoted by the service
8. Mechanisms for advanced decision-making (for example advanced directives or crisis cards) are offered
9. **People develop their own discharge plans (suggested by panel member)**
10. **People contribute to their discharge plans (suggested by panel member)**
11. **Services have an easily accessible complaints procedure, with results collated and reported (suggested by panel member)**

Operational

The following are examples of how people are involved in how services are run (involvement at an operational level). This has been divided into 5 sub categories.

Training, support and payment for service users to be involved

This sub category is training and support for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 3.

1. The organisation has a policy on payment for involvement
2. Training is offered for people who get involved
3. People are offered payment for their time

Involvement in staff recruitment and training

This sub category is involvement in staff recruitment and training. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 5.

1. Service users contribute to a professionally led training session
2. Service users contribute to design the training curriculum
3. Service users contribute to the development of training
4. Service users are part of professional development assessment process
5. At least one service user is part of an interview panel for all staff recruitment

Involvement in delivering and evaluating services

This sub category is involvement in delivering and evaluating services. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 7.

1. Services provide clear information about medical treatments written by professional in clear language
2. Service users contribute to the production of official information
3. Service users are provided with information written by service users
4. Service users choose their peer support
5. The service addresses the physical health needs of service users
6. User focussed monitoring is in place
7. **Service users act as peer reviewers (suggested by panel member)**

Mechanisms for involvement

This sub category is mechanisms for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

1. The service has a regular meeting that service users can attend to get involved
2. Decision-makers from services visit service users at service user led meetings
3. Meetings are structured to ensure equality of involvement for all participants
4. Online, social networks and other remote techniques are offered to enable involvement without physical presence
5. Story-telling and drama presented by service users is used as a way to present service user views
6. Service users engage in outreach work to ascertain views of other service users and report back
7. **Involvement mechanisms are routinely provided in accessible formats (for example: braille, large print, audio, signer for events) (suggested by panel member)**
8. **Involvement mechanisms always offer alternatives to online mechanisms (suggested by panel member)**
9. **All websites conform to W3C accessibility standards (suggested by panel)**

Measurable impact

This sub category is impact of involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 4.

1. Services demonstrate improved mental health outcomes linked to involvement
2. Services demonstrate improved health outcomes linked to involvement
3. Services demonstrate reduced discrimination linked to involvement
4. Barriers to involvement are identified and overcome

Strategic

The following are examples of how people are involved in how services will be in the future (involvement at a strategic level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 7.

1. Several service users sit on the governing body
2. Service developments are clearly influenced by user focussed monitoring
3. Service users define the purpose and direction of the service
4. Service users are involved in contract specification
5. **Service users contribute to evaluating service tenders (suggested by panel)**
6. Service user involvement is explicitly included as part of clinical governance
7. Service users are given the resources required to develop their own services

The second round online

The second round opened on 18 June 2013 and closed on 1 July. Reminders were issued on 25 June to panel members who had not completed the round. To avoid a repeat the technical problems that occurred with the first round, I sent a separate note out manually asking people to let me know if they had not received the second round invite and also reminding them to check their spam/junk email, folders/filters.

Completing the second round

All panel members received an email notifying them that the second round been completed. This email included a link that enabled all panel members to see the results of the first round. In addition to the automatically generated email, I sent all panel members and note thanking them for their contribution, instructions about how to receive payment for their contribution, and asking them to let me know whether they wished to be informed about further developments.

Activity after the second round

Administration of payments was completed by NSUN, but I received a number of questions regarding payments and continue to provide information and contact details to support this process. I maintained a list of panel members who wish to remain in contact with this initiative, and they will be sent copies of all reports resulting from this study.

Panel member comments

In addition to the rankings, panel members provided a range of comments. These comments were collected and collated using NVivo 10 software, coded for emerging themes and used to help the process of seeking consensus. The comments were also used to help draw broader conclusions and these form part of the discussion in chapter 6. All comments made were automatically made available to other panel members on completion of each round. Comments were not attributed to individuals and even I, as software administrator, did not know who had made individual comments.

4.8 CONCLUSION

This chapter has described the research activity undertaken. This included the resources available, the work completed to choose a question type, select the Delphi panel, a description of the characteristics of the Delphi panel members, including their involvement experience, and a complete list of the potential indicators placed before the panel, over the two rounds.

The next chapter will set out the findings from the Delphi panel.

5 FINDINGS

5.1 INTRODUCTION

This chapter presents the expert opinions expressed by the panel. In order to present the large volume of information, it is structured as follows:

- Delphi first round
    - Individual level
        - Rankings for Q1, in table and graphic form
        - Brief summary of panel comments on the content of their responses to Q1
    - Operational level
        - Rankings for Q2 – Q6, in table and graphic form; interspersed with…
        - Brief summary of panel comments on the content of their responses to Q2 – Q6
    - Strategic level
        - Rankings for Q7, in table and graphic form
        - Brief summary of panel comments on the content of their responses to Q7
- Between the rounds
    - Panel comments on the process, drawn from the first round and other correspondence
    - Suggests for the indicators
    - Changes made for second round
- Delphi second round
    - Individual level
        - Rankings for Q1, in table and graphic form
        - Brief summary of panel comments on the content of their responses to Q1
    - Operational level
        - Rankings for Q2 – Q6, in table and graphic form; interspersed with…
        - Brief summary of panel comments on the content of their responses to Q2 – Q6
    - Strategic level
        - Rankings for Q7, in table and graphic form
        - Brief summary of panel comments on the content of their responses to Q7
    - Panel comments on the process, drawn from the second round and other correspondence

5.2 DELPHI FIRST ROUND

5.2.1 Consensus levels

In order to accept consensus that an example is effective, it would need to have a very strong average rank, as a starting point, for the best examples, I sought consensus with an average rank above the 10th percentile and at the bottom below the 67th percentile; but with the caveats that strict adherence to percentiles could miss important information, I also took the number of times ranked first, the overall distribution of average ranks, and text comments into account. A more detailed discussion of my approach to consensus is given in chapter 3.

5.2.2 Individual level

The first question (Q1) presented to the panel is set out below, followed by their ranks and then their comments:

The following are examples of how people are involved in their own care and treatment (involvement at an individual level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 14.

Panel rankings: individual level

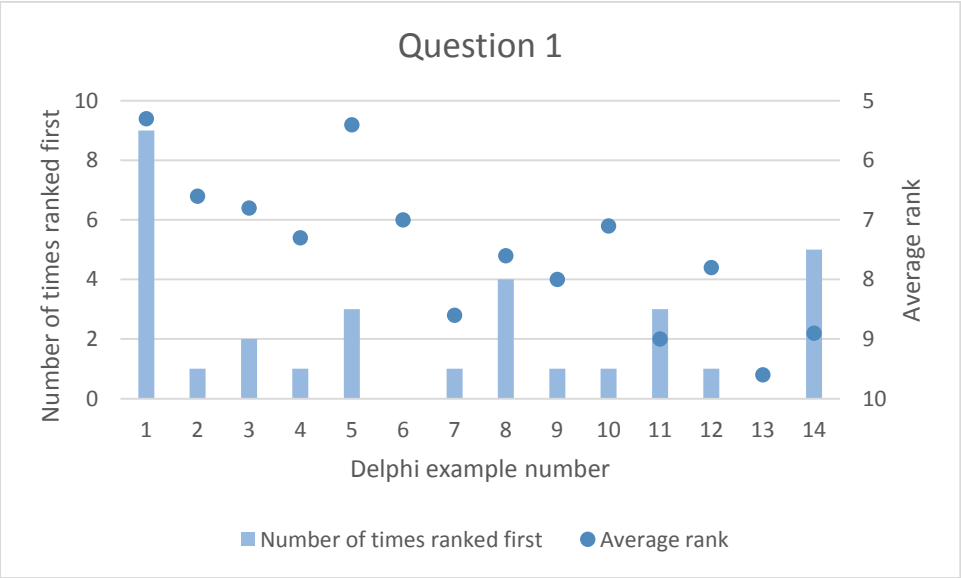
Table 5.1, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.1

Q1	Involvement example description	Average rank	Number of times ranked first	As %
1	People using services identify their own needs	5.3	9	28%
2	The service/treatment goals are set by service users	6.6	1	3%
3	The service/treatment goals are life orientated rather than symptom orientated	6.8	2	6%
4	The service/treatment goals are jointly set by professionals and service users	7.3	1	3%
5	People have a choice of services/treatments	5.4	3	9%
6	People have the positive and negative effects of treatments clearly explained	7	0	0%
7	Service users are actively trained to achieve treatment goals	8.6	1	3%
8	Professionals actively share responsibility and decision-making with service users	7.6	4	13%
9	All discussions about services/treatments are in plain English	8	1	3%
10	The service/treatment focuses on the service user's strengths and potential	7.1	1	3%
11	Service user led self-help groups are promoted by the service	9	3	9%
12	People are encouraged/trained to engage in self-management	7.8	1	3%
13	People are actively encouraged to find their own sources of support	9.6	0	0%
14	Mechanisms for advanced decision-making (for example advanced directives or crisis cards) are offered	8.9	5	16%
		Total	32	100%

Figure 5.1, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.1



Panel Comments: individual level
24 panel members commented on their responses to question 1.

2 people gave very detailed accounts of their experiences of mental ill-health, the services they received and the impact this had on their responses, 2 people gave brief details of their personal experience and why it affected their responses. 4 people gave detailed explanations of their responses, 2 people gave brief explanations of some of their responses.

A number of themes were repeated by 3 or more panel members. The importance of relationships with professionals was mentioned by 7 people; the importance of goal setting, by 7 people; the importance of recovery, by 5 people; choice, by 4 people; and the value of self-help groups or peer support by 4 people.

A number of other themes were raised by 1 or 2 panel members in response to this question including: the gap between policies and practice, the value of self-management, active involvement in decision-making and people setting their own outcomes.

Consensus: individual level
Example numbers 1 and 5, had average ranks above the 10th percentile, they were both ranked top by a reasonable number of panel members (9 and 3 respectively) and consensus on these examples was clear.

6 examples fell below the 67th percentile, but two of these were ranked first by a reasonable number of panel members (example 14 was ranked first by 5 people and example 11, by 3) so I judged consensus to be reached on the other 4. These were examples 7, 9, 12 and 13.

5.2.3 Operational level

The next 5 questions (Q2 - Q6) presented to the panel are set out below, followed by their ranks and then their comments:

The following are examples of how people are involved in how services are run (involvement at an operational level). This has been divided into 5 sub categories.

Panel Rankings: Training, support and payment for service users to be involved

This sub category is training and support for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 6.

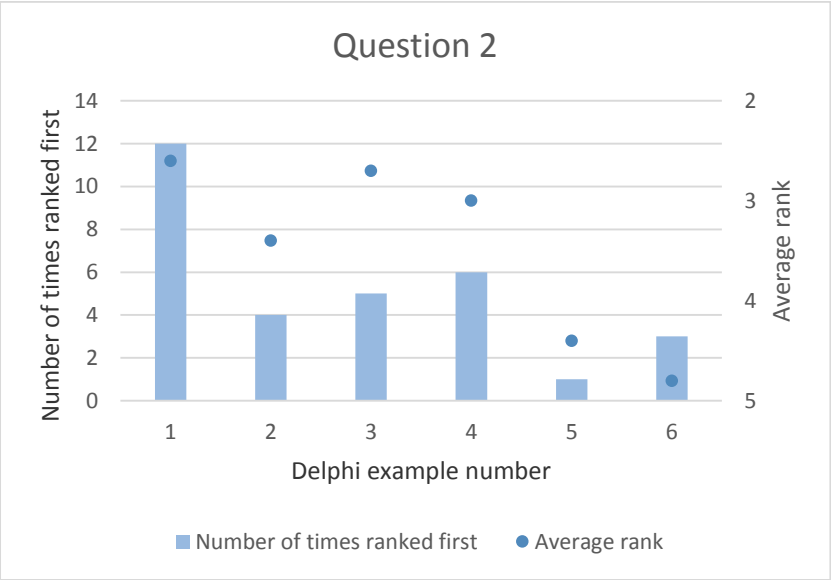
Table 5.2, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.2

Q2	Involvement example description	Average rank	Number of times ranked first	As %
1	People involved are supported meet together regularly	2.6	12	39%
2	The organisation has a policy on payment for involvement	3.4	4	13%
3	Training is offered for people who get involved	2.7	5	16%
4	People are offered payment for their time	3	6	19%
5	People have their expenses paid at time of, or after the involvement	4.4	1	3%
6	People have their expenses paid in advance	4.8	3	10%
		Total	31	100%

Figure 5.2, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.2



Panel Comments: Training, support and payment for service users to be involved
26 panel members commented on their responses to this question. 3 people gave detailed explanations of their responses; 5 people gave brief explanations of their responses.

8 people highlighted training for involvement as important; 6 people explained the importance of payments in terms of people feeling valued and their contribution being taken seriously; 5 people highlighted the difficulties of getting involved when people are very poor; 4 people expressed concerns about the impact of payment on receipt of benefits; 3 people highlighted payment or support (or the lack of it) as highlighting a gap between policy and practice. The remaining comments covered technicalities of payment policies or types of support offered.

Consensus: Training, support and payment for service users to be involved
Only example number 1, had an average rank above the 10th percentile, although the next best average ranked example (number 3) was close, there was also a large difference in the number of times ranked first by panel members (12 and 5 respectively) so I took consensus on example 1 only.

Examples 5 and 6 fell below the 67th percentile, and they also had the lowest number of people ranking them first (example 6 was ranked first by 3 people and example 5, by 1) so I judged consensus to be reached on examples 5 and 6.

Panel Rankings: Involvement in staff recruitment and training
This sub category is involvement in staff recruitment and training. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

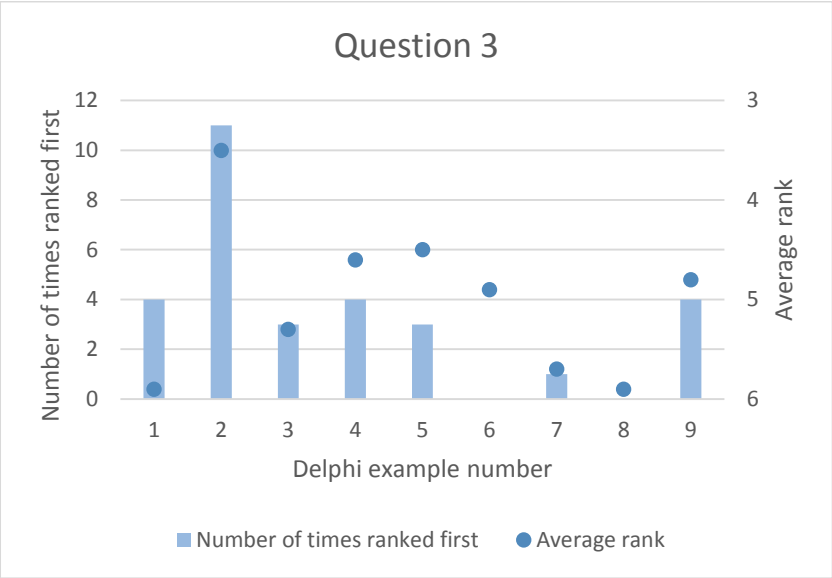
Table 5.3, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.3

Q3	Involvement example description	Average rank	Number of times ranked first	As %
1	Service users deliver training independently or professionals or other trainers	5.9	4	13%
2	Service users deliver training in partnership with professionals	3.5	11	37%
3	Service users contribute to a professionally led training session	5.3	3	10%
4	Service users contribute to design the training curriculum	4.6	4	13%
5	Service users contribute to the development of training	4.5	3	10%
6	Service users are part of professional development assessment process	4.9	0	0%
7	Service users contribute to staff job descriptions	5.7	1	3%
8	Service users are involved in shortlisting candidates	5.9	0	0%
9	At least one service user is part of an interview panel for all staff recruitment	4.8	4	13%
		Total	30	100%

Figure 5.3, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.3



Panel Comments: Involvement in staff recruitment and training

17 panel members commented on their responses to this question. 6 people gave brief explanations of their responses. 2 people gave brief details of their personal experience and how it affected their responses. 4 people gave detailed explanations of their responses, 1 person gave a detailed description of their personal experience and how it affected their responses.

9 people expressed the importance of involvement in recruitment, and 8 in training. The issue of diversity of people involved and the problem of tokenism in involvement were both raised.

Consensus: Involvement in staff recruitment and training

Only example number 2 had an average rank above the 10th percentile, no other example was close in either average rank or number of times ranked first, so I took consensus on example 2 only.

Examples 1, 7 and 8 fell below the 67th percentile, there was no other average rank particularly close, and none of these examples had notably high number of ranked firsts so I judged consensus to be reached on these examples.

Panel Rankings: Involvement in delivering and evaluating services

This sub category is involvement in delivering and evaluating services. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

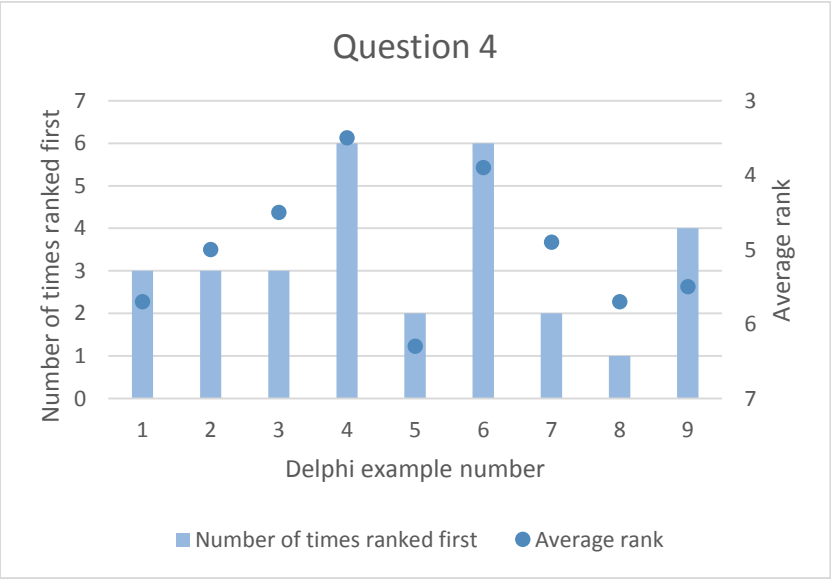
Table 5.4, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.4

Q4	Involvement example description	Average rank	Number of times ranked first	As %
1	Services provide clear information about medical treatments written by professional in clear language	5.7	3	10%
2	Service users contribute to the production of official information	5	3	10%
3	Service users are provided with information written by service users	4.5	3	10%
4	Service user involvement is led by a service user in a paid role	3.5	6	20%
5	Peer support is part of the service but led by professionals	6.3	2	7%
6	Service has peer workers who are paid employees	3.9	6	20%
7	Service users choose their peer support	4.9	2	7%
8	The service addresses the physical health needs of service users	5.7	1	3%
9	User focussed monitoring is in place	5.5	4	13%
		Total	30	100%

Figure 5.4, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.4



Panel Comments: Involvement in delivering and evaluating services

19 panel members commented on their responses to this question. 2 people gave brief explanations of their responses. 3 people gave brief details of their personal experience and how it affected their responses.

10 people mentioned the importance of physical health; 7 people mentioned self-help or peer support; 3 people, the importance of good, clear information; 3 people, medication; and 2 people highlighted weigh as a health and medication issue.

Consensus: Involvement in delivering and evaluating services

Only example number 4, had an average rank above the 10th percentile, but the next best average ranked example (number 6) was very close, and shared in the highest number of times ranked first by panel members (6 times), and they both had average ranks clearly better than the next example (number 3) so I took consensus on examples 4 and 6.

3 examples fell below the 67th percentile, but the distribution of 2 of them with 1 example just above the percentile was very tight, and the number times ranked first was reasonable even. As example 5 fell far below the others, I took consensus on that example only.

Panel Rankings: Mechanisms for involvement

This sub category is mechanisms for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

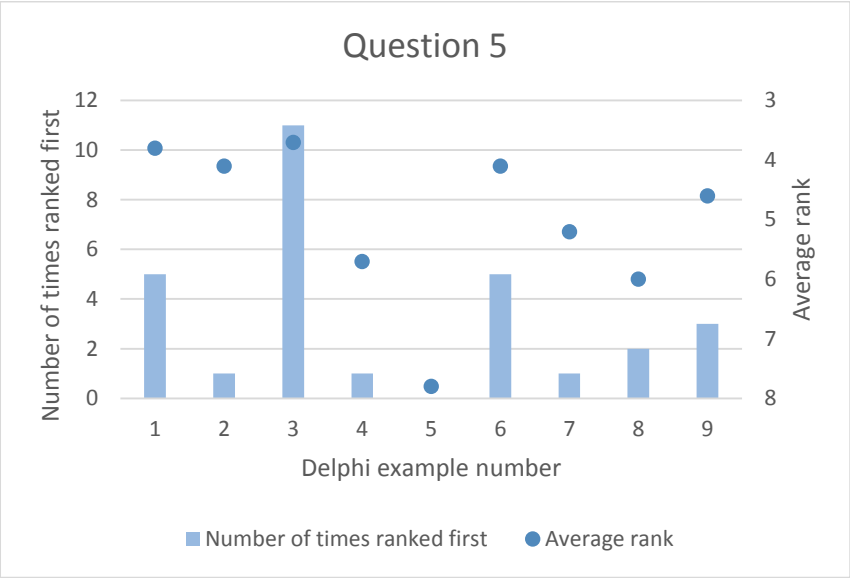
Table 5.5, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.5

Q5	Involvement example description	Average rank	Number of times ranked first	As %
1	The service has a regular meeting that service users can attend to get involved	3.8	5	17%
2	Decision-makers from services visit service users at service user led meetings	4.1	1	3%
3	The service has an independent service user panel	3.7	11	38%
4	Some of the service's operational meetings include one or two service users	5.7	1	3%
5	Games based approaches to involvement are used	7.8	0	0%
6	Meetings are structured to ensure equality of involvement for all participants	4.1	5	17%
7	Online, social networks and other remote techniques are offered to enable involvement without physical presence	5.2	1	3%
8	Story-telling and drama presented by service users is used as a way to present service user views	6	2	7%
9	Service users engage in outreach work to ascertain views of other service users and report back	4.6	3	10%
		Total	29	100%

Figure 5.5, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.5



Panel Comments: Mechanisms for involvement
19 panel members commented on their responses to question 5.

1 person gave a more detailed account of their personal experience and the impact this had on their responses, 2 people gave brief details of their personal experience and how it affected their responses. 1 person gave a detailed explanation of their responses, 4 people gave brief explanations of some of their responses.

8 people commented on drama, and 6 on games, both positively and negatively, with 3 people expressing the view that they were patronising; 6 people mentioned independent service user panels or fora, 4 people mentioned the importance of outreach work to ensure people's views were captured if they couldn't make events or meetings; 2 people raised concerns about tokenism.

Consensus: Mechanisms for involvement
Only example number 3, had an average rank above the 10th percentile, although the next best average ranked example (number 1) was close, there was also a large difference in the number of times ranked first by panel members (11 and 5 respectively) so I took consensus on example 3 only.

Examples 4, 5 and 8 fell below the 67th percentile, there was no other average rank particularly close, and none of these examples had notably high number of ranked firsts so I judged consensus to be reached on these examples.

Panel Rankings: Measurable impact
This sub category is impact of involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 6.

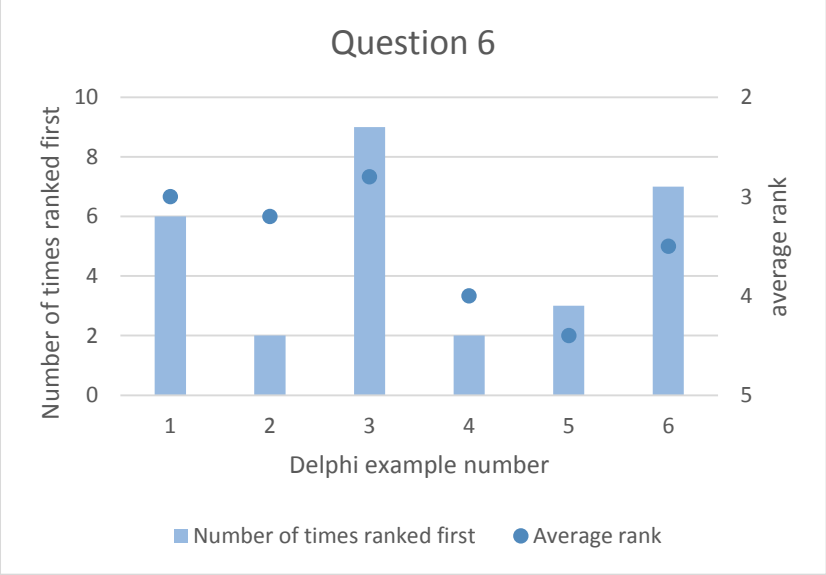
Table 5.6, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.6

Q6	Involvement example description	Average rank	Number of times ranked first	As %
1	Services demonstrate improved mental health outcomes linked to involvement	3	6	21%
2	Services demonstrate improved health outcomes linked to involvement	3.2	2	7%
3	Services demonstrate improved quality of life linked to involvement	2.8	9	31%
4	Services demonstrate reduced discrimination linked to involvement	4	2	7%
5	Barriers to involvement are identified and reported	4.4	3	10%
6	Barriers to involvement are identified and overcome	3.5	7	24%
		Total	29	100%

Figure 5.6, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.6



Panel Comments: Measurable impact

17 panel members commented on their responses to question 6.

1 person gave a more detailed account of their personal experience and the impact this had on their responses, 3 people gave brief details of their personal experience and how it affected their responses. 5 people gave brief explanations of some of their responses.

6 people mention barriers, but 4 people thought identifying them was a waste of time without overcoming them; 5 people highlighted physical health or wellbeing; 5 people mentioned discrimination and stigma, either as very important either as an activity in itself, or as an outcome of involvement.

Consensus: Measurable impact

Only example number 3, had an average rank above the 10th percentile, although the next best average ranked example (number 1) was close, there was also a difference in the number of times ranked first by panel members (9 and 6 respectively) so I took consensus on example 3 only.

Examples 4 and 5 fell below the 67th percentile, although there was no other average rank particularly close, and neither of these examples had notably high number of ranked firsts, discrimination was mentioned as important by five people in their comments, so I judged consensus to be reached on example 5 only.

5.2.4 Strategic level

The final question (Q7) presented to the panel is set out below, followed by their ranks and then their comments:

The following are examples of how people are involved in how services will be in the future (involvement at a strategic level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 11.

Panel Rankings

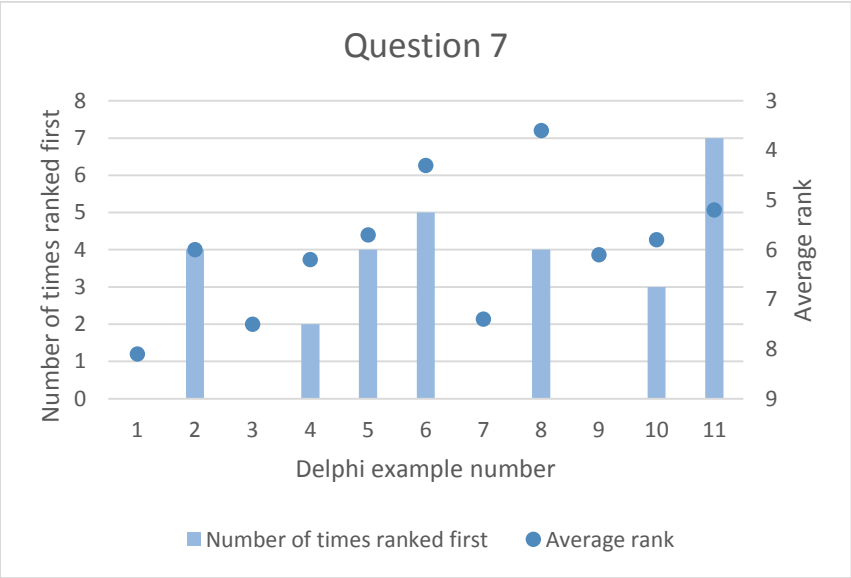
Table 5.7, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.7

Q7	Involvement example description	Average rank	Number of times ranked first	As %
1	Service users attend the governing body	8.1	0	0%
2	Several service users sit on the governing body	6	4	14%
3	Service users review and report to the governing body	7.5	0	0%
4	Service developments are clearly influenced by user focussed monitoring	6.2	2	7%
5	Service users define the purpose and direction of the service	5.7	4	14%
6	New services are jointly designed or co-produced by service users and professionals	4.3	5	17%
7	Services demonstrate any changes linked to involvement	7.4	0	0%
8	Service users are involved in the commissioning of services	3.6	4	14%
9	Service users are involved in contract specification	6.1	0	0%
10	Service user involvement is explicitly included as part of clinical governance	5.8	3	10%
11	Service users are given the resources required to develop their own services	5.2	7	24%
		Total	29	100%

Figure 5.7, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.7



Panel Comments: Strategic level
19 panel members commented on their responses to question 7.

1 person gave a more detailed account of their personal experience and the impact this had on their responses, 2 people gave brief details of their personal experience and how it affected their responses. 5 people gave brief explanations of some of their responses.

7 people mentioned working in partnership; 5 people mentioned governance, including 2 who specifically mentioned clinical governance; 3 people mentioned commissioning; 4 people mentioned complete service user control of resources, 3 positively, 1 negatively.

Consensus: Strategic level
Example numbers 6 and 8, had average ranks above the 10th percentile, consensus on these examples was clear.

4 examples fell below the 67th percentile, but the distribution of 1 of them (example 4) with 2 examples just above the percentile was very tight, and the number times ranked it was first exceeded them. As examples 1, 3 and 7 fell far below them others, and had no first ranks, I took consensus on those examples only.

5.3 First round consensus summary

5.3.1 The most effective examples

The following achieved consensus as being the most effective examples of service user involvement:

Individual level

People using services identify their own needs
People have a choice of services/treatments

Operational Level

People involved are supported meet together regularly
Service users deliver training in partnership with professionals
Service user involvement is led by a service user in a paid role
Service has peer workers who are paid employees
The service has an independent service user panel
Services demonstrate improved quality of life linked to involvement

Strategic level

New services are jointly designed or co-produced by service users and professionals
Service users are involved in the commissioning of services

5.3.2 The least effective examples

The following achieved consensus as being the least effective examples of service user involvement:

Individual level

Service users are actively trained to achieve treatment goals
All discussions about services/treatments are in plain English
People are encouraged/trained to engage in self-management
People are actively encouraged to find their own sources of support

Operational Level

People have their expenses paid at time of, or after the involvement
People have their expenses paid in advance
Service users deliver training independently or professionals or other trainers
Service users contribute to staff job descriptions
Service users are involved in shortlisting candidates
Peer support is part of the service but led by professionals
Some of the service's operational meetings include one or two service users
Games based approaches to involvement are used
Story-telling and drama presented by service users is used as a way to present service user views
Barriers to involvement are identified and reported

Strategic level

Service users attend the governing body
Service users review and report to the governing body
Services demonstrate any changes linked to involvement

5.4 BETWEEN THE ROUNDS

5.4.1 Comments on the process

Panel members made 20 comments on the process during their responses to round 1. At least 5 different panel members submitted comments, but it is not possible to identify how many did in total as comments are anonymised. All but 2 of the comments expressed criticisms or difficulties.

Ten comments expressed difficulty in ranking items, on the 5 comments where the difficulty was explained in more detail it was a difficulty in choosing between items that people would have liked

to rank equally. For question 3, 1 person described it as easy to rank and 2 as difficult. 3 further comments stated that there were too many options to choose from. 2 people commented that the study was very time consuming.

Five comments were critical of the presentation of the questions, 1 of these related to the size on screen, 1 commented on grouping recruitment and training in the same question. The other 3 related to the statement of question 6 “This sub category is impact of involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 6.” not matching the options presented as they were not, in themselves, ways of involving people. Unfortunately the website did not allow the text of a question to be altered, so this stayed as it was for the second round. This probably also accounted for 1 comment that the panel member did not understand the question. 2 people commented on not understanding the items to be ranked themselves, 1 user focussed monitoring and the 1 games for involvement.

Two positive comments were made by panel members, 1 found question 3 “pretty easy to rank” and 1 stated “all the questions made me realise how important involvement is to wellbeing”.

5.4.2 Other comments not directly related to indicators

A number of comments not directly related to indicators were expressed by panel members. The five most frequent are outlined below.

Tokenism

Tokenism is a recurring criticism of both some approaches to involvement and people’s experience of it. Where it relates involvement processes; comments refer to involvement at stages where decisions have already been made, minor contributions to long or complicated processes, attendance at meetings without full membership of decision-making bodies or small numbers of service users in large groups. Where tokenism refers to people’s own experience of involvement, it relates to being present but not heard, or being treated marginally compared to other participants.

Medication

Medication is explicitly mention both as an area in which involvement is often poor in terms of information, choice and consent; and that excessive or inappropriate medication and its negative effects are a barrier to effective involvement.

Benefits

Concerns were expressed about the impact either the activity of involvement, or payment for involvement may have on an individual’s benefit entitlement.

Recovery

The concept of recovery was mentioned a number of times. This was usually seen as a positive principle but concerns were expressed where recovery goals were set or assessed by professionals rather than individuals themselves.

Diversity

The importance of involving a diverse range of people was highlighted by a number of panel members.

5.4.3 Additional panel indicator suggestions

Round 1 included an additional question which asked people for any examples of effective mental health service user involvement they would suggest adding to the second round. 22 panel members

responded to this request; 18 of these responses either explained people's responses to the previous questions in more detail or gave examples of the types of involvement they had person experience of from the indicator examples listed in the questions. 5 people gave more detailed examples of involvement in training or education; 3 on an independent panel or forum; and 2 on involvement in commissioning.

Two new potential indicators were explicitly mentioned in the text: involvement as a peer reviewer and involvement in discharge planning, 4 people referred to emails that they had sent or would send including potential indicators, 6 new examples were submitted by email.

5.4.4 Changes made for second round

Consensus was reached on 6 items for question 1, 3 items for question 2, 4 items for question 3, 3 items for question 4, 4 items for question 5, 2 items for question 6, and 4 items question 7. These items were removed the second round. Additional items suggested by panel members during round one were added. 3 items were added for question 1, 1 for question 4, 3 for question 5, and 1 for question 7.

5.5 DELPHI SECOND ROUND

5.5.1 Individual level

The first question (Q1) presented to the panel is set out below, followed by their ranks and then their comments:

The following are examples of how people are involved in their own care and treatment (involvement at an individual level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 11.

Panel rankings: Individual level

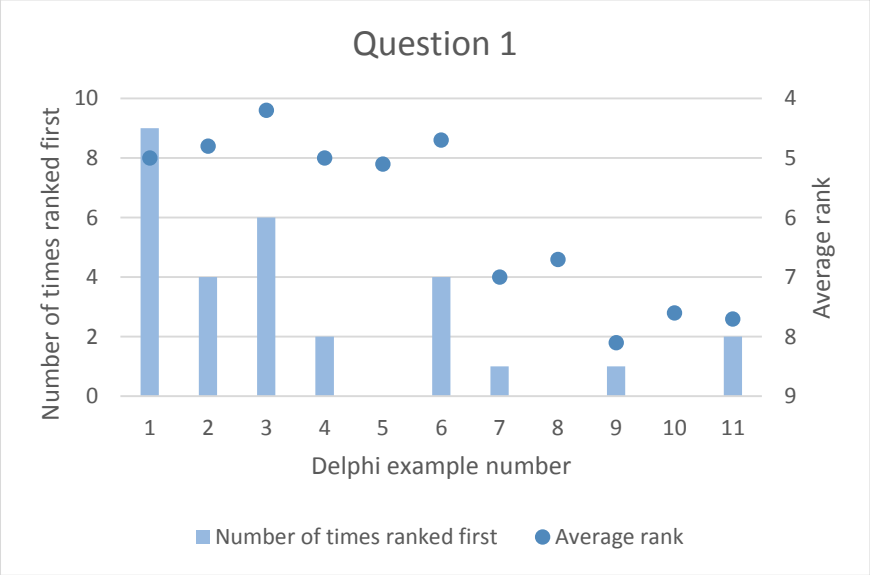
Table 5.8, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.8

Q1	Involvement example description	Average rank	Number of times ranked first	As %
1	The service/treatment goals are set by service users	5	9	31%
2	The service/treatment goals are life orientated rather than symptom orientated	4.8	4	14%
3	The service/treatment goals are jointly set by professionals and service users	4.2	6	21%
4	People have the positive and negative effects of treatments clearly explained	5	2	7%
5	Professionals actively share responsibility and decision-making with service users	5.1	0	0%
6	The service/treatment focuses on the service user's strengths and potential	4.7	4	14%
7	Service user led self-help groups are promoted by the service	7	1	3%
8	Mechanisms for advanced decision-making (for example advanced directives or crisis cards) are offered	6.7	0	0%
9	People develop their own discharge plans	8.1	1	3%
10	People contribute to their discharge plans	7.6	0	0%
11	Services have an easily accessible complaints procedure, with results collated and reported	7.7	2	7%
		Total	29	100%

Figure 5.8, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.8



Panel Comments: individual level
Eighteen panel members commented on their responses to question 1.

Four people explained their responses in some detail.

Three new examples of involvement were introduced to this question: 2 on discharge planning and 1 on complaints procedures. These subjects generated a good number of comments: 4 on discharge planning and 7 on complaints, these comments were a mix of positive and negative on both. 3 people commented on the importance of involvement in goal setting and 3 on information about medication.

Consensus: individual level
For the second round, I sought consensus at the top end only. The remaining examples would not be accepted as the best examples of effective mental health service user involvement.

Example numbers 3 and 6, had average ranks above the 10th percentile, they were both ranked top by a reasonable number of panel members (6 and 4 respectively) and consensus on these examples was reached.

5.5.2 Operational level

The next 5 questions (Q2 - Q6) presented to the panel are set out below, followed by their ranks and then their comments:

The following are examples of how people are involved in how services are run (involvement at an operational level). This has been divided into 5 sub categories.

Panel Rankings: Training, support and payment for service users to be involved
This sub category is training and support for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 3.

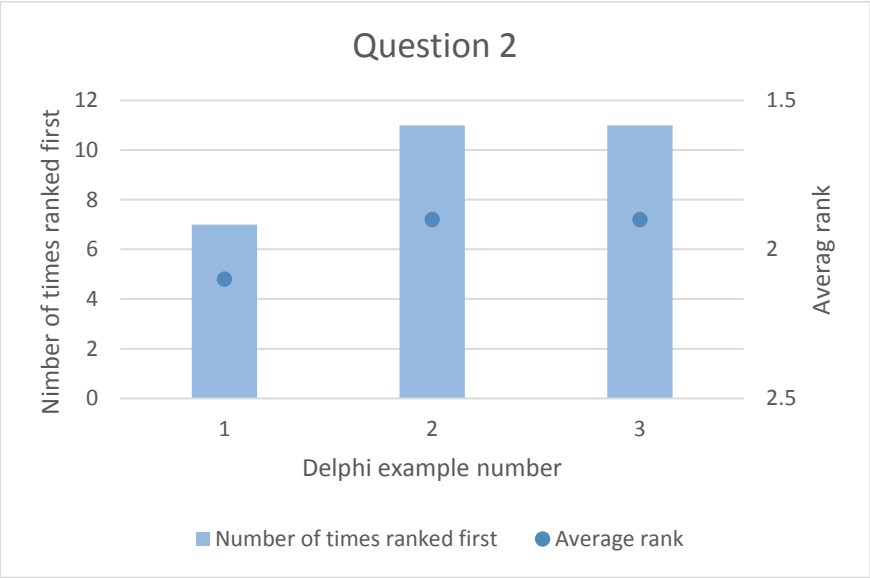
Table 9, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.9

Q2	Involvement example description	Average rank	Number of times ranked first	As %
1	The organisation has a policy on payment for involvement	2.1	7	24%
2	Training is offered for people who get involved	1.9	11	38%
3	People are offered payment for their time	1.9	11	38%
		Total	29	100%

Figure 5.9, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.9



Panel comments: Training, support and payment for service users to be involved
Although there were only 3 items to rank, 18 panel members commented on their responses to question 2.

Nine people explained their responses, 2 people commented it was difficult to rank and 1 that it was easy to rank.

The comments reflected a balanced view of the relative effectiveness of payment, with 7 comments and training with 6.

Consensus: Training, support and payment for service users to be involved
Examples 2 and 3, had an average rank above the 10th percentile, leaving example 1 below; so consensus was reached on examples 2 and 3.

Panel Rankings: Involvement in staff recruitment and training
This sub category is involvement in staff recruitment and training. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 5.

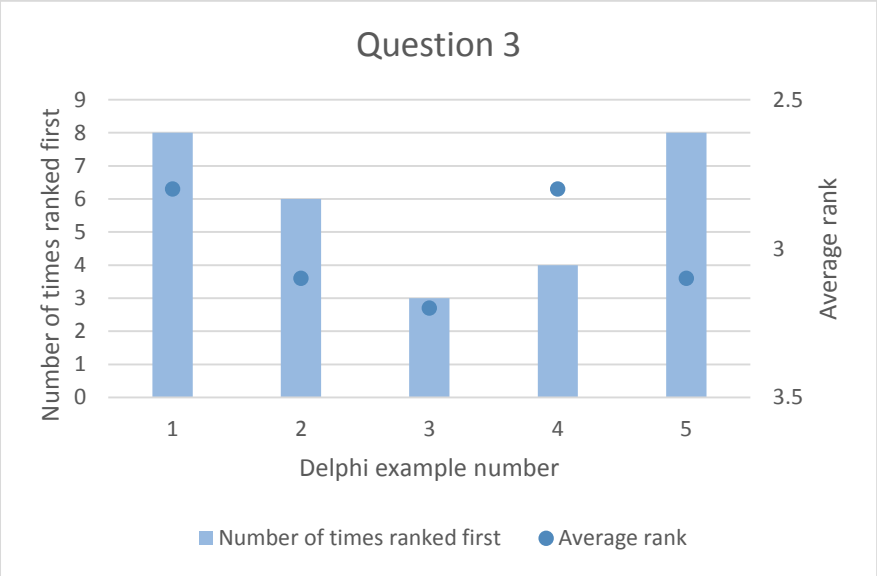
Table 5.10, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.10

Q3	Involvement example description	Average rank	Number of times ranked first	As %
1	Service users contribute to a professionally led training session	2.8	8	28%
2	Service users contribute to design the training curriculum	3.1	6	21%
3	Service users contribute to the development of training	3.2	3	10%
4	Service users are part of professional development assessment process	2.8	4	14%
5	At least one service user is part of an interview panel for all staff recruitment	3.1	8	28%
		Total	29	100%

Figure 5.10, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.10



Panel Comments: Involvement in staff recruitment and training
Sixteen panel members commented on their responses to question 3.

Twelve explained their responses in some detail. 7 people gave examples of their involvement in training or education; 3 commented on recruitment. 5 people raised concerns about tokenism in involvement, both in training and recruitment processes.

Consensus: Involvement in staff recruitment and training
Examples 1 and 4 had an average rank above the 10th percentile, no other example was close in average rank, so I took consensus on these 2.

Panel Rankings: Involvement in delivering and evaluating services

This sub category is involvement in delivering and evaluating services. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 7.

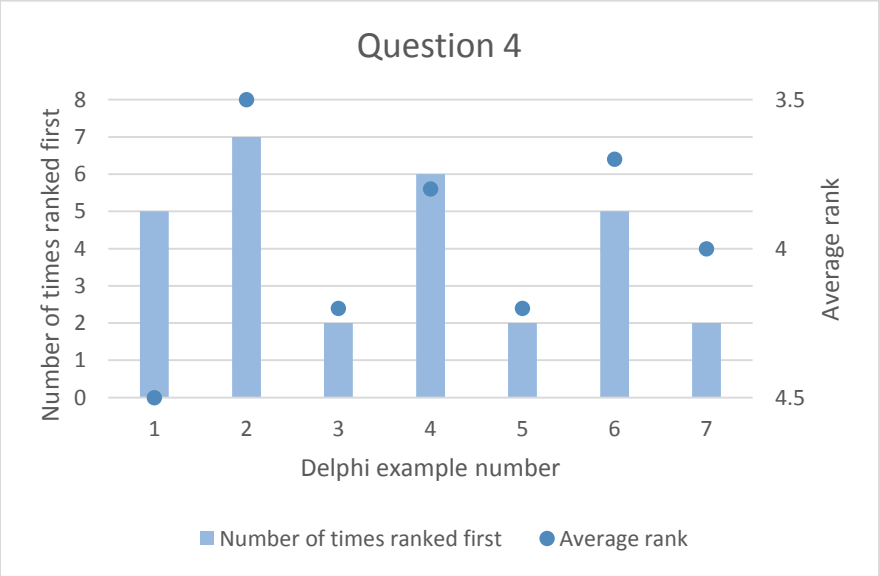
Table 5.11, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.11

Q4	Involvement example description	Average rank	Number of times ranked first	As %
1	Services provide clear information about medical treatments written by professional in clear language	4.5	5	17%
2	Service users contribute to the production of official information	3.5	7	24%
3	Service users are provided with information written by service users	4.2	2	7%
4	Service users choose their peer support	3.8	6	21%
5	The service addresses the physical health needs of service users	4.2	2	7%
6	User focussed monitoring is in place	3.7	5	17%
7	Service users act as peer reviewers	4	2	7%
		Total	29	100%

Figure 5.11, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.11



Panel Comments: Involvement in delivering and evaluating services
Thirteen panel members commented on their responses to question 4.

Nine people explained their responses in some detail, 5 people commented on the importance of physical health and expressed concern that this wasn't taken seriously in mental health services.

Consensus: Involvement in delivering and evaluating services
Only example number 2, had an average rank above the 10th percentile, it also had the greatest number of ranked first so I took consensus on that example.

Panel Rankings: Mechanisms for involvement
This sub category is mechanisms for involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 9.

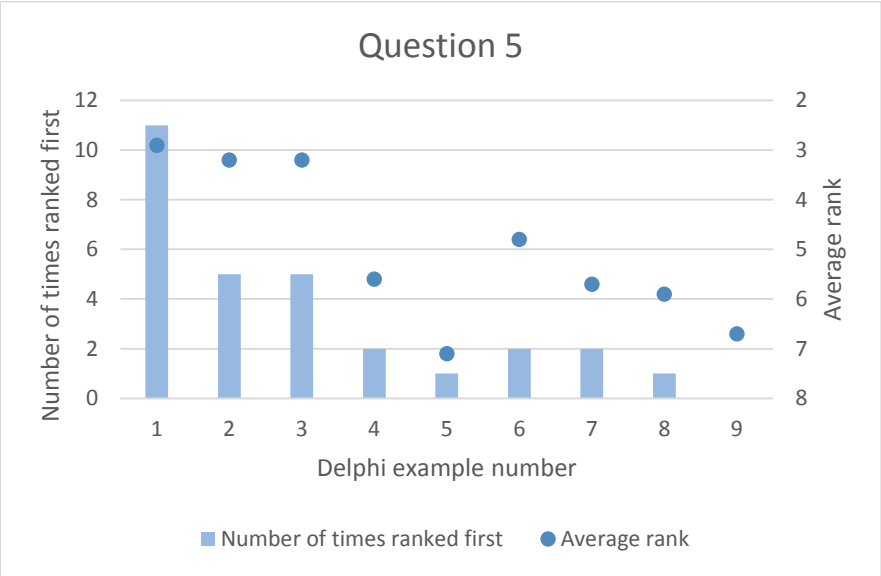
Table 5.12, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.12

Q5	Involvement example description	Average rank	Number of times ranked first	As %
1	The service has a regular meeting that service users can attend to get involved	2.9	11	38%
2	Decision-makers from services visit service users at service user led meetings	3.2	5	17%
3	Meetings are structured to ensure equality of involvement for all participants	3.2	5	17%
4	Online, social networks and other remote techniques are offered to enable involvement without physical presence	5.6	2	7%
5	Story-telling and drama presented by service users is used as a way to present service user views	7.1	1	3%
6	Service users engage in outreach work to ascertain views of other service users and report back	4.8	2	7%
7	Involvement mechanisms are routinely provided in accessible formats (for example: braille, large print, audio, signer for events)	5.7	2	7%
8	Involvement mechanisms always offer alternatives to online mechanisms	5.9	1	3%
9	All websites conform to W3C accessibility standards	6.7	0	0%
		Total	29	100%

Figure 5.12, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.12



Panel Comments: Mechanisms for involvement
Fourteen panel members commented on their responses to question 5.

Nine people explained their responses in some detail. Online tools prompted 4 comments, both in favour and against. 3 people expressed the importance of outreach, going to people rather than expecting them to come to events.

Consensus: Mechanisms for involvement
Only example number 1, had an average rank above the 10th percentile, it also had the greatest number of ranked first so I took consensus on example 1 only.

Panel Rankings: Measurable impact
This sub category is impact of involvement. Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 4.

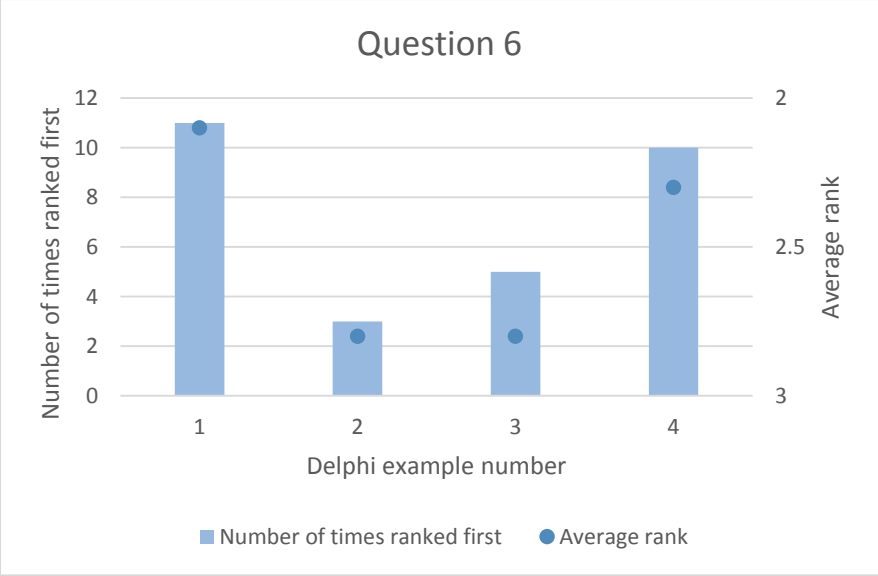
Table 13, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.13

Q6	Involvement example description	Average rank	Number of times ranked first	As %
1	Services demonstrate improved mental health outcomes linked to involvement	2.1	11	38%
2	Services demonstrate improved health outcomes linked to involvement	2.8	3	10%
3	Services demonstrate reduced discrimination linked to involvement	2.8	5	17%
4	Barriers to involvement are identified and overcome	2.3	10	34%
		Total	29	100%

Figure 13, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.13



Panel Comments: Measurable impact

Thirteen panel members commented on their responses to question 6.

Seven people explained their responses in some detail. 1 person described this question as difficult to rank, 1 as easier to rank.

Five people commented on barriers to involvement, and 4, on the impact of involvement on discrimination.

Consensus: Measurable impact

Only example number 1, had an average rank above the 10th percentile, it also had the greatest number of ranked first so I took consensus on example 1 only.

5.5.3 Strategic level

The final question (Q7) presented to the panel is set out below, followed by their ranks and then their comments:

The following are examples of how people are involved in how services will be in the future (involvement at a strategic level). Please rank them in order of how effective you think they are as a way of involving people where the most effective is ranked 1 and the least effective is ranked 7.

Panel Rankings: Strategic level

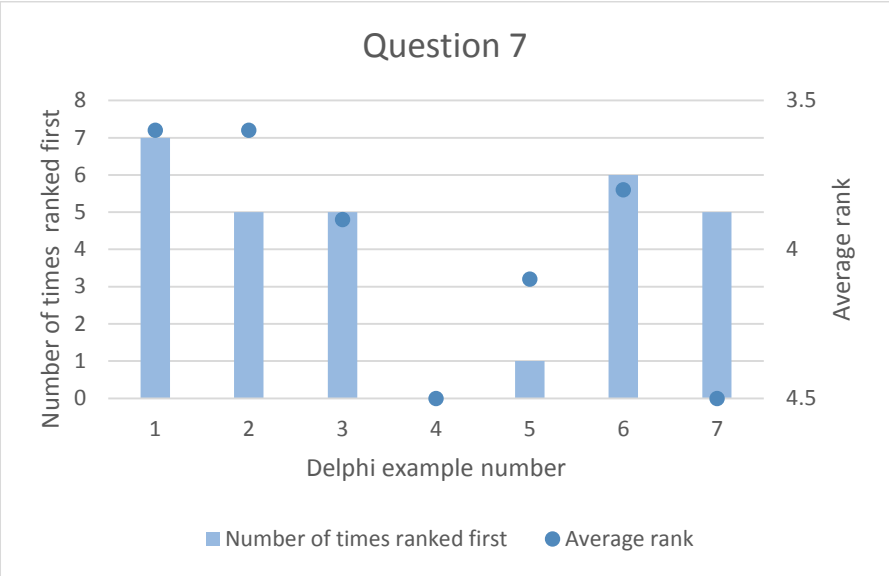
Table 5.14, below, lists the response number, a brief description of the involvement example, the average rank received from panel members, and the number of panel members who ranked the item first (numerically and as a percentage of all panel members).

Table 5.14

Q7	Involvement example description	Average rank	Number of times ranked first	As %
1	Several service users sit on the governing body	3.6	7	24%
2	Service developments are clearly influenced by user focussed monitoring	3.6	5	17%
3	Service users define the purpose and direction of the service	3.9	5	17%
4	Service users are involved in contract specification	4.5	0	0%
5	Service users contribute to evaluating service tenders	4.1	1	3%
6	Service user involvement is explicitly included as part of clinical governance	3.8	6	21%
7	Service users are given the resources required to develop their own services	4.5	5	17%
		Total	29	100%

Figure 5.14, below, shows the number of times ranked first, and average rank for each example item. Note that the scale for the average rank (on right hand side) increases from top to bottom to reflect that a lower average rank is better.

Figure 5.14



Panel Comments: Strategic level
Seventeen panel members commented on their responses to question 7.

Six people their responses in some detail. No one described this question as difficult to rank, and 1 described it as not difficult to rank.

Four people commented on service users controlling resources or leading services; all were in favour but 2 of those described it either idealistic or unrealistic.

Consensus: Strategic level
Example numbers 1 and 2, had average ranks above the 10th percentile, consensus on these examples was clear.

Panel Comments: Process comments
In responses to the second round of questions, the comment "difficult to rank" was made 13 times: 4 times for question 1; twice for questions 2, 3, 4, and 5; and once for question 6. Questions 2, 6 and 7 were described as easy or not difficult to rank once, each.

5.6 A MISTAKE BETWEEN ROUNDS AND HOW THE DELPHI PROCESS WAS AFFECTED

One item from question 5 in round one fell below the 67th percentile and should therefore have been removed for the second round. The item "Story-telling and drama presented by service users is used as a way to present service user views" was left in by mistake. In the second round, this item score lowest for both average rank and number of times ranked first. Although the item should not have been included, its inclusion and subsequent position demonstrated that (this item at least) was scored consistently across both rounds and there was therefore no adverse impact on the results of the Delphi process.

5.7 CONCLUSION

This chapter has described the findings of the two rounds of the Delphi process. As a result of presenting 69 potential indicators to the Delphi panel of 38 people with experience of, and expertise

in mental health service user involvement, consensus was reached on 21 indicators of effective mental health service user involvement. These are summarised in table 5.15, below.

Table 5.15 – The final indicators

Level	Indicator
Individual	People using services identify their own needs
	People have a choice of services/treatments
	The service/treatment goals are jointly set by professionals and service users
	The service/treatment focuses on the service user's strengths and potential
Operational	People involved are supported meet together regularly
	Training is offered for people who get involved
	People are offered payment for their time
	Service users deliver training in partnership with professionals
	Service users contribute to a professionally led training session
	Service users are part of professional development assessment process
	Service user involvement is led by a service user in a paid role
	Service has peer workers who are paid employees
	Service users contribute to the production of official information
	The service has an independent service user panel
	The service has a regular meeting that service users can attend to get involved
	Services demonstrate improved quality of life linked to involvement
	Services demonstrate improved mental health outcomes linked to involvement
Strategic	New services are jointly designed or co-produced by service users and professionals
	Service users are involved in the commissioning of services
	Several service users sit on the governing body
	Service developments are clearly influenced by user focussed monitoring

6 DISCUSSION

6.1 INTRODUCTION

This research has sought to establish a way of measuring effective mental health service user involvement. In this chapter I discuss how this could be achieved, based on the evidence drawn from published literature and reviewed and assessed in a structured way, by a diverse group of people with a wealth of experience and expertise in service user involvement.

Through the course of my research, two things have become apparent: although involvement has shifted from a radical rarity to commonplace policy, there is still a significant difference between policy and practice; and there is significant variation between different people's experience of involvement. This difference is based on a range of characteristics of both the individuals and the environment in which they get involved.

6.2 THE WORLD HAS CHANGED (A BIT)

Even as recently as ten years ago, I would have had considerable difficulty gathering an expert panel with so much hand on experience of service user involvement across such diverse settings. In the last ten years, national service user networks have been established in England (National Survivor User Network, NSUN), Scotland (Voices of eXperience, VoX) and Wales (National Service User and Carer Forum), all of which have relationships with their respective national governments. There can be no doubt that effective service user involvement is happening day in, day out across the country at all levels, and that it is making a positive difference. I have found broad consensus across policy documents, research findings, peer reviewed literature and service user publications that involving mental health service users is the right thing to do; though it is not always clear why people want to do it.

Although there are an increasing number of studies of particular involvement exercises, there remains little solid research into the impact of service user involvement as a whole, nor is there anything approaching allowing people to assess the effectiveness of their own involvement initiatives.

6.3 INVOLVEMENT, LEADERSHIP AND CO-PRODUCTION

There is an interesting distinction emerging between three concepts that until recently have been considered together under service user involvement as an umbrella term: co-production, service user led and peer led. The differences occur around the roles service users and professionals play and the range of experiences that service users bring.

- Co-production involves both professionals and service users bringing their skills and experience to a joint process that creates something new.
- Service user led means that people who have direct experience of service use are in control.
- Peer-led implies that there is a common experience that is more than simply having used services, for example a shared diagnosis, a shared ethnic background or experience of a particular service; this distinction is relatively new (though the concept of peer support is firmly grounded in self-help movements that precede most service user involvement) and may continue to develop.

As consensus was reached on a number of indicators, a clear pattern emerged which favoured those that described co-production. This finding was unexpected, co-production is a relatively new term and was not in widespread use when I completed my literature review; nor did the term occur in the title or abstract of any of the literature I reviewed. In English health and mental health services, new terms arrive regularly: many of these disappear without trace, some become highly influential and change services and others get adopted in name only with little effect on services or outcomes. The term co-production has been received with a degree of cynicism by service users who are actively involved. Concern has been expressed that the word will be applied to processes and initiatives that are no different to how they have always been.

Although co-production had not occurred widely in academic research, the concept has been identified and developed by a number of organisations with a focus on social or policy research, including the New Economics Foundation (NEF), the National Endowment for Science |Technology and the Arts (NESTA) and the Social Care Institute for Excellence (SCIE). SCIE described the use of the term co-production as follows:

> "The term 'co-production' is increasingly being applied to new types of public service delivery in the UK, including new approaches to adult social care. It refers to active input by the people who use services, as well as – or instead of – those who have traditionally provided them" (Needham, 2009).

The Delphi panel's preference for co-production occurred at each level. At the individual level "the service/treatment goals are jointly set by professionals and service users" was favoured over "the service/treatment goals are set by service users". At the operational level "service users deliver training in partnership with professionals" and "service users contribute to a professionally led training session" were favoured over "service users deliver training independently of professionals or other trainers". At the strategic level "new services are jointly designed or co-produced by service users and professionals" was favoured over "service users are given the resources required to develop their own services", a full list of indicators that suggest co-production is set out below in table 6.1.

Table 6.1 –Co-production indicators

Level	Indicator
Individual	The service/treatment goals are jointly set by professionals and service users
Operational	Service users deliver training in partnership with professionals
	Service users contribute to a professionally led training session
	Service users contribute to the production of official information
	The service has a regular meeting that service users can attend to get involved
Strategic	New services are jointly designed or co-produced by service users and professionals
	Several service users sit on the governing body

In a recent discussion paper, NESTA has identified some of the challenges associated with the recent popularity of the term. In a discussion paper (Boyle and Harris, 2009) found no agreed definition of co-production and as a result used a set of criteria to establish whether a service met its criteria for co-production and table 6.2, below, sets out the indicators they use.

Table 6.2 - Reproduced from Boyle (2009)

		Responsibility for design of services		
		Professionals as sole service planner	**Professionals and service users/ community as co-planners**	**No professional input into service planning**
Responsibility for delivery of services	**Professionals as sole service deliverers**	Traditional professional service provision	Professional service provision but users/ communities involved in planning and design	Professionals as sole service deliverers
	Professionals and users/ communities as co-deliverers	User co-delivery of professionally designed services	**Full co-production**	User/ community delivery of services with little formal/ professional
	Users/ communities as sole deliverers	User/ community delivery of professionally planned services	User/ community delivery of co-planned or co-designed services	Self-organised community provision

The results of this research are consistent with NESTA's approach and findings. The panel members expressed concern about tokenism and reinforced the literature findings of a gap between policy and practice but still consistently favoured co-production approaches over those that were service user led or peer led. It seems to be a product of a number of factors:

- The concept of mental health service user involvement is strongly associated with joint work rather than service user or peer led work.
- High importance was put on the relationship between service users and professionals not just the nature of the service itself.
- Working with professionals was thought to be more effective than working independently of them, both in terms of improving services and outcomes, and also as a way of challenging discrimination, through social contact for professionals with service users in positive roles.

If this reflects a wider view, then the current high profile of co-production may lead to more widespread effective service user involvement and this research clearly indicates the need for further work and the subset of indicators set out in table 6.1, above could be used to assess co-production within a service.

This finding has also prompted discussion elsewhere and I was asked to produce a summary of the discussion and findings around co-production for the Welsh Government, this briefing is attached as appendix h and recommendations are made in chapter 7.

6.4 INVOLVEMENT LEVELS

Throughout this research I have divided involvement into three levels: individual, operational and strategic. As noted in chapter 2, terms of reference, this is a widely used approach. One of the

advantages of this approach is that it allows people to see where time and effort is being expended and where benefits can be drawn.

6.4.1 Individual

Historically, service user involvement has referred to involvement in services, either at an operational or strategic level, including involvement in training and educating professionals and practitioners. Acknowledging the importance of involvement at an individual level is more recent and still not universally seen as service user involvement. Involvement at an individual level is, however, important because it has the potential to addresses two fundamental problems facing effective mental health service user involvement: power inequalities and the representativeness of people who get involved.

Discrimination and stigma are identified as key barriers to effective involvement. People with a psychiatric diagnosis are perceived as outsiders in a number of ways including the way we are treated in law. Mental health legislation in the England and Wales (and many other countries) permits (or even prescribes) actions to be taken against individuals with a psychiatric diagnosis that would not be permitted against any other person. Most of this legal discrimination is based around individual care and treatment, the power of self-determination is legally removed from people and granted to others to exercise on their behalf. The threshold for these legal judgements is based on a professional clinical decision about mental illness and wellness, rather than about the capacity to make the decision.

Involvement at an individual level seeks to redress this fundamental power inequality. It helps to shift the notion that a psychiatric diagnosis or mental illness renders an individual incapable of looking after themselves. It sits comfortably with both the rights based history of the survivor movement and the choice/personalisation approach of the consumerist policy developments of the last 20 years.

One of the most significant barriers to effective involvement cited by professionals and service providers is that people who are actively involved are not representative of most people they work with. This perception is important, whether it reflects reality or not. In order to get involved at an operational or strategic level, people need to be comfortable working alongside others in structured settings for organisational purposes. Mental health service users who can do this effectively are probably as representative of all service users as the others around the table are of the general population - that is to say they are the proportion of the populations who are competent and comfortable operating at that level. It is probably true that these skills do not represent the skills displayed by most people in their role as recipient of mental health services.

Involvement in one's own care is different. We have a unique and valuable insight into our own condition/state of mind/distress. People may not always be able to articulate this, nor is it always heard when they do, but developing a strong focus on people understanding themselves and actively contributing to their own care makes service user involvement accessible to everyone, without any need to represent any one else at all. It is also possible to build on involvement at an individual level to involve people in other ways. Someone who has, for example, identified a personal care need that is not currently provided may be encouraged to get involved in planning future services if that is likely to lead to their own needs being better met. It is likely that this will benefit many other service users as well. The consensus indicators strongly reflect a desire for people to identify their own needs and have a choice of interventions that focus on potential not symptom reduction. The importance of working with professionals is reflected in the consensus on service/treatment goals being jointly set.

6.4.2 Operational

Involvement at an operational level, in the day to day running of services, has always been at the heart of service user involvement. This is reflected in the literature, the experience of the Delphi panel members, and in the number and breadth of indicators presented to them.

Involvement at an operational level is often shorthand for meetings, and many of the barriers to effective involvement are linked to meetings, and in particular, who is present, who sets the agenda, how meetings are conducted, how meetings are reported, and most important of all, what happens as a result of them.

Although meetings are clearly important, and having an appropriate number of skilled, well prepared and properly supported service users present is necessary, it is not sufficient, to make service user involvement effective. Many decisions are made outside of meetings and many more could be made in ways that involve more people more effectively and lead to better decisions.

The second most widespread area of involvement at the operational level is involvement in the education and training of mental health professionals. It is well established, respected by service users, professionals and students alike, and appears to be effective with many demonstrable benefits to all parties; the key issues for the consensus on indicators was the relative roles of, and relationship between professionals and service users, and in particular how equal the partnership is throughout the process from development to delivery. Consensus was reached on, for example, training in partnership and contributing to a professionally led session. This area is well represented in the literature.

6.4.3 Strategic

Involvement in planning and service development have, like involvement at an operational level, been established for some time. Involvement at this level also relies heavily on meetings, but has been increasingly informed by service user involvement in research and evaluation, where this feeds into service development. Involvement at a strategic level places a significant burden on those who take part and requires high levels of skills and understanding to do effectively, and as a result of this, people involved in this level tend to be even more likely to be perceived as unrepresentative. Service users who get involved at this level will find they are alongside people in well paid roles with organisational support behind them; yet they are often expected to fulfil these roles on a voluntary basis with little or no administrative or organisational support. This level offers the greatest opportunity for significant change over time as it is less bound by the way things are currently done.

There have been a number of creative alternatives to meetings for service development, including game based approaches, drama and increased use of emerging technologies like social networks and mobile devices like smartphones and tablets. These tend to divide opinion with some people strongly favouring them and others finding them exclusive or patronising and no consensus was reached on more unusual mechanisms. This reaction highlights that mechanisms chosen will have an impact on who chooses to get involved and suggests the need for a range of mechanism to ensure that diverse voices are heard. Where consensus was reached, for example on involvement in commissioning and several people sitting on governing bodies, this reflects an understanding of the current strategic structures in place and a desire to be engaged in, and influencing, these structures.

6.5 LITERATURE

Any attempt to measure effective involvement needs to start with the evidence base, what we already know. There is, however, a significant challenge to this. The peer reviewed literature found

during this research offered a partial view of involvement. Very little of the "evidence" was authored by mental health service users, although they contributed to a number of papers reviewed. In order to redress this imbalance more resources are needed for service user led, and co-produced research and service users need to be encouraged and supported to write more.

The greatest volume of literature by far was that relating to education and training; although it is clearly the case that service user involvement is well established in this area, the literature over represents this. This is almost certainly because the professionals involved seem more inclined to study and write about what they do. One positive result of this is that one of the areas in which service user involvement is well established and broadly welcomed is also relatively well documented and tested. Much of this learning is transferable and, of course, many of the people who are educated and trained by service users will move on to providing care or managing or developing services and some of the influence of service user involvement in their training and education should travel with them.

Although the literature is partial in both its authorship and coverage, there are a number of themes that occur frequently. These include the gap between policy and practice; attitudes towards, discrimination against or stigma attached to people who experience mental ill-health; the value of service user involvement when it is done well and the need to actively support involvement if it is to be effective.

The most significant problem with the existing literature from the service user involvement perspective is that it contains very little generated wholly by service users. This matters for two reasons: much of the current activity in service user involvement is going largely undocumented and often untested; and any resources that are applied on the basis of published evidence will be disproportionately focussed on activities led by those who publish.

6.6 PANEL

The people who formed the Delphi panel demonstrated the breadth and quality of mental health service user involvement in practice. They demonstrate what can be achieved with involvement and have identified many of the obstacles still in place. Members of the panel came from every region of England. Their ages were distributed fairly evenly between 26 and 76, there were slightly more women than men.

The ethnic makeup of the panel provided a limited degree of diversity. The proportions of white, Irish, Bangladeshi, Indian and Pakistani people all exceeded the proportion in the English population as a whole, based on the most recent census data. Some ethnic groups, however, were not present on the panel at all. Although a panel of 38 people is unlikely to reflect the diversity of the population of England, I was disappointed by the absence of people from African, African Caribbean or other Black backgrounds.

This absence is a matter for concern, people, and particularly young men, from Black populations are known to be disproportionately subject to compulsory treatment and detention (Singh et al., 2007 offer a detailed analysis). This suggests that their views should be actively sought as an essential part of changing this pattern of treatments that has persisted for many years.

There are a number of reasons why people from this background may not have reached the panel: they seem to be under represented in most forms of service user involvement; the networks I used to recruit from do not reach people from this background; actively involved people from Black backgrounds may be less inclined or less able to respond to this consultation exercise; or the chosen

approach, or reliance on online tools may not be appropriate for some reason. Whatever the reason, it is clearly important that further work is done to ensure that any standards developed involve people from this ethnic background.

I have used the same networks to recruit to previous consultation exercises and have found good responses from Black communities before. The response from non-white English people as a whole was strong, with a significant proportion coming from an Asian background, which at least suggests that the approach taken was not one that work only for white English service users.

The panel had a very broad experience of service user involvement across all levels and in a variety of ways. All but two articulated involvement at an operational level, reflecting the literature and my experience that this is the most common level of involvement. The vast majority were involved at a strategic level as well, and more than half were involved in their own care. Although this proportion is higher than might be expected for the least common level of involvement, it is not surprising that people who are so actively involved in so many ways take a disproportionate degree of involvement in their own care. Although this group could not be taken as representative of the population of people using mental health services as a whole, they were still a group of people directly and immediately affected by mental ill-health. Two people explicitly withdrew from the study between Delphi rounds for mental health reasons, and one joined at second round stage having missed the first round for mental health reasons.

The amount of time and effort that panel members put into their responses was impressive. I had expected that people would simply rank the indicators and possibly suggest one or two additional indicators. In practice, panel members put a lot of effort into explaining their rankings, many going into a lot of detail and drawing on their personal experience of involvement, or experiences that were reported to them.

It is clear from the comments made by panel that the one single element that can make or break service user involvement is the relationship between mental health services users and professionals. Where the relationship is good, it makes for some of the most effective service user involvement; where it is poor, it can block effective involvement altogether. This supports the notion that the essence of effective service user involvement IS the relationship and effective involvement becomes the way that relationship is established, developed, managed and assessed.

6.7 Delphi Process

I found the Delphi process both informative and frustrating and this was clearly a view shared by the panel members. Limiting people to give unique ranks rather than allowing joint rankings forced them to make choices and the most frequent complaint about the process was the difficulty of making these choices. This criticism was most frequent when there were a large number of items to choose from, and I tried to reduce this issue by setting a lower threshold for consensus at the low end than the high end; that is to say I was quicker to accept consensus that an indicator was not useful at all than that it was a very good indicator. Further, although I accepted this difficulty and tried to mitigate it where possible, forcing people to choose ensured that preferences were expressed and this gave useful ranking information that would not have been possible if people had applied equal ranking.

Framing the questions was much more difficult than I expected. The approach I eventually used to identify the indicators of effective involvement required people to rank the examples on the basis that an organisation doing A was more effective at involvement than one doing B. I tried a number

of approaches and piloted a couple before settling on this one. Worked examples were provided with the materials to make the process as clear as possible; I also responded to a number of emails seeking clarification.

The iterative nature of the process provided a rare opportunity for people to understand other panel members' rationale for their rankings, and to adjust their thinking if they wished. In most research approaches, this information would be controlled and mediated by the researcher. This enhanced transparency was in keeping with the empowering nature of this research and was explicitly appreciated by a number of the panel members. The iterative nature also had its downside with one panel member complaining about having to answer (mostly) the same questions again.

The output from the site was limited to average rank and number of times an item was ranked first. This, alongside the comments made by panel members, seemed quite sufficient for the purpose of identifying consensus.

6.8 CONSENSUS INDICATORS

The purpose of the research was to identify, by consensus, some potential indicators of effective mental health service user involvement. Following two rounds of the Delphi process using a combination of analysis of ranks and associated comments, I found a good degree of consensus on a number of indicators at all levels and in a number of specific areas.

6.8.1 Consensus on the most effective Involvement at an individual level

Clear consensus was reach on four indicators at an individual level. The indicators cover a range of approaches to involvement and would, if applied to any system of care giving, ensure that the rhetoric of "user centred services" is reflected in practice.

People using services identify their own needs

This marks a distinct shift from the tradition medical approach of a diagnosis applied by a clinical professional to a self-determined, needs based approach. This relies on a change in the nature of the relationship between professionals and the people they serve. This is independent of, and complementary to, the diagnostic process and reflect the different emphases that professionals and service users place on the nature of mental ill-health; with clinicians emphasising conditions and symptoms and individuals priorities overcoming difficulties and getting on with their lives in the context of their diagnosis/condition.

People have a choice of services/treatments

The concept of choice has always been important in service user involvement. There are caveats of course, the choice needs to be genuine and the choice needs to be informed. Making a choice is part of people taking responsibility for themselves, part of learning. The choices made may be wrong, but that does not invalidate the importance of choice. Even if professionals never made mistakes, it remains a fundamental right of people to make their own choices, where they have the capacity to do so. Learning from the consequences of choices made is part of the "recovery" process.

In order for choices to be a realistic proposition, a range of services and treatments must be available to choose between; and there must be sufficient accessible information available to enable people to make an informed choice.

The service/treatment goals are jointly set by professionals and service users

The collaborative nature of this indicator illustrates one of the recurring themes of this research, service user involvement is about the relationship between services (and the people who deliver

them) and the people they serve. That jointly set goals gained consensus and goals set by service users alone narrowly failed to do so reflects the perceived importance of a constructive relationship between professionals and service users rather than a desire to ignore professionals and their expertise that is sometimes associated with service user involvement. It also provides a recognition that working together is more likely to have a positive impact than working in isolation. Many comments acknowledged the value of professionals' contributions, particularly when people were genuinely unable to set their own goals due to distress or mental ill-health. Joint goals were seen as more meaningful than professionally set goals and more likely to be supported by services than goal set solely by service users.

The service/treatment focuses on the service user's strengths and potential

This marks a move away from the deficit model of mental illness towards a strengths based, forward looking approach. The concept of focusing on what people can do, rather than what they cannot do has significant advantages: it gives people hope, it builds confidence, and it casts people in a positive role, as part of the solution rather than a problem. One complicating factor mental health professionals face is that they tend to see people when they are at their most disabled or in crisis; this gives the professional a rather partial view of the individual and may explain why they tend to focus on illness and symptoms rather than strengths. More regular and frequent contact outside crisis situations would encourage a more complete understanding of the impact of mental ill-health in the context of people's lives.

Two other items received high level of support but fell short of consensus: *the service/treatment goals are set by service users*, and *the service/treatment goals are life orientated rather than symptom orientated*. These complement the indicators that did reach consensus. A number of people said that in an ideal world they would rate goals set by service users higher than jointly set goals but for their experience that jointly set goals were more likely to be taken seriously and have a positive impact. Life orientated goals were seen as important, but not necessarily a priority for people's services, rather they were something that people should do for themselves or in peer groups. Table 6.3, below, summarises the individual level indicators on which consensus was reached.

Table 6.3 – Individual level

People using services identify their own needs
People have a choice of services/treatments
The service/treatment goals are jointly set by professionals and service users
The service/treatment focuses on the service user's strengths and potential

6.8.2 Consensus on the most effective Involvement at an operational level

In order to make this, the most developed of levels of involvement, manageable, I have divided it into sub categories that broadly reflect the following: supporting people who get involved, key areas they get involved in, how the involvement happens and what difference it makes. Consensus was reached on a number of indicators across all of these sub categories.

Training, support and payment for service users to be involved

Many people recognised that involvement can come at a cost to those who get involved. In order for involvement to be effective, it is necessary to mitigate that cost and offer some benefits to those involved. The following indicators would help identify organisations that recognise and address this.

People involved are supported meet together regularly

Most people considered involvement to be at its most effective when done in some kind of collective way, rather than as an individual pursuit. This approach allows people to share skills, support each other and gives them a greater range of perspectives to draw on. People get into the habit of being involved and have the opportunity to see the impact of their involvement over time.

Training is offered for people who get involved

Training performs two key functions for people who get involved: it increases their skills and effectiveness and the impact of their involvement and it offers them the opportunity for personal development. The offer of training can be an incentive to get involved and a personal benefit of involvement. Service user involvement, when done well, is good for people's self-esteem and self-confidence and training can contribute to that process.

People are offered payment for their time

Being valued was a key component of the rationale for payment. Some people also thought that their involvement would be taken more seriously if it were paid for. Payment also moves service users towards parity with other stakeholders, the majority of whom will be involved as part of a paid role. There were, however, a number of issues identified around benefits and payment that need to be addressed to avoid payment being a barrier to involvement for some people.

Involvement in staff recruitment and training

Throughout this section people commented on the importance of service users and professionals working together in an integrated and coherent way. Approaches that set service users apart from professionals, either as trainers or recruiters, were seen as tokenistic. Where service users and professionals trained together, or where service users were integrated into professional training and development, this was seen as normalising the notion of service users as contributors to training and professional development; reinforcing the importance of the relationship to effective involvement.

Service users deliver training in partnership with professionals

Although a small number expressed a preference for service users training on their own, most thought this was not taken as seriously as jointly delivered training; particularly when it was a single day (or even session) as part of a much larger course. It may also help to reinforce positive attitudes towards the capabilities of service users as trainers; enabling them to be seen as an equal contributor to a professional training process.

Service users contribute to a professionally led training session

Whilst it is important to acknowledge the value of service user led training, it has become clear that much professional training still either ignores or undermines service user led training. Service users who contribute to professionally led training are able to shape professional behaviour and, provided the contribution is genuinely jointly delivered, is likely to influence people who would be more resistant to service user led training.

Service users are part of professional development assessment process

One of the limitations of any kind of training is that the impact is time limited if the messages are not reinforced by practice. Involving service users in the professional development assessment process ensures that service users' priorities form part of the process for deciding how good, in professional practice terms, the professional is. This should ensure that professional development addresses service user priorities as a fundamental requirement of practice.

A note on recruitment

Many people described their experience of being involved in recruitment processes as tokenistic. They were generally not involved in developing job descriptions or shortlisting candidates. They also felt that they were not listened to as part of a panel. Consensus was not reached on involvement in staff recruitment

Involvement in delivering and evaluating services

All the indicators below emphasise the importance of integrating service user involvement into the service rather than tacking it on as an afterthought. That the roles involved are paid roles within the service is seen as indicating that they are taken seriously and valued.

Service user involvement is led by a service user in a paid role

A number of Delphi panel members had been in paid involvement roles and were able to critically analyse the experience. Service user involvement as a paid role enables people to dedicate more time than would otherwise be possible. It also gives people access to support and resources from within the organisation and facilitated contact between staff and service users that would be more difficult as an outsider. Some people identified the risk of potential conflicts of interest when service users and providers come into conflict, it could be difficult for a paid worker to take action which may annoy their employer. Protection would need to be in place to ensure that service user involvement workers are protected from inappropriate pressure as staff.

Service has peer workers who are paid employees

Peer support is becoming increasingly recognised as an import part of the support people need to manage their mental ill-health. It is now established as part of the services that many statutory and voluntary sector service providers offer. There has been a growth in paid peer workers recently, similar benefits and cautions apply to these workers as to service user involvement workers.

Service users contribute to the production of official information

In order for people to make informed choices, they need to have access to good quality accessible information. One way to ensure that information is delivered in a form and style that is appropriate and usable is to engage service users in the production of the information. People who have recently, or are currently, using services are well placed to ensure that the information provided meets their needs. People felt this would be a good way of avoiding jargon and inaccessible language.

Mechanisms for involvement

The mechanisms that involved people collectively were generally regarded as preferable to those that were one-to-one. A number of people mention the emergence of online and social media as mechanisms for involvement; but these appear to be at an early stage of development and people were not wholly convinced about their value. People pointed out that many service users still did not have access to the internet or social media without going to a resource centre or internet café and that involvement mechanisms like this should not automatically be considered free or accessible. The reaction to less conventional approaches was interesting, many people found the idea of using drama or games patronising and exclusive rather than adding to the diversity of involvement mechanisms.

The service has an independent service user panel

Independent panels which were service user only proved to be very popular, with the benefit of meeting together on a regular basis and being able to set their own agenda before feeding into the

agenda of the service provider. This approach also enable people to support each other through involvement.

The service has a regular meeting that service users can attend to get involved

The regularity and frequency of meetings is important. It allows people and organisations to get into the habit of involvement, to provide regular feedback and to reinforce the link between involvement and positive change. It allows for continuity of involvement of people from all interested groups which encourages relationship building. It also allows for succession planning so that a diverse cohort of service users can become involved over time.

Independent panels that have a link with a regular and frequent service involvement meetings offer a straightforward but potentially powerful and effective mechanism for service user involvement that can address many of the concerns that both service users and providers have regarding involvement.

Measurable impact

The primary purpose of effective mental health service user involvement should be to improve services from a service user perspective. This purpose forms the basis of most policy statements (at both a strategic and operational level). Though some people hold the view that the impact of involvement is intrinsically unmeasurable; it is clear that being able to demonstrate the benefit of any activity is important when it comes to justifying applying resources to it. In short service user involvement has a cost which may be borne by the service or the service user; is it worth it? The two indicators where consensus was reached seek to demonstrate improvements in both mental health outcomes and broader quality of life.

Services demonstrate improved mental health outcomes linked to involvement

The primary role of mental health services should be to produce beneficial mental health outcomes. Many organisational policies suggest that involvement has an important contribution to make to this process. Showing that this is happening in practice helps to demonstrate that involvement in an organisation is more than rhetoric.

Services demonstrate improved quality of life linked to involvement

Although mental health services are primarily about mental health, there is increasing recognition of the importance of placing mental ill-health in the broader context of people's physical health and broader life. Mental health service user involvement should make people's lives better; an important component of effective involvement is demonstrating this.

Mental health services are complicated systems, and demonstrating that any particular outcome can be attributed to service user involvement requires thought and effort. Initiatives that have a degree of continuity and include feedback loops can help with this.

Consensus on the indicator: *barriers to involvement are identified and overcome* was only narrowly missed. It is likely, however, that any effective involvement approach would achieve this as a matter of course which may explain why, though regarded as important by many, it was not agreed as an indicator. Table 6.4, below, summarises the operational level indicators on which consensus was reached.

Table 6.4 – Operational level

People involved are supported meet together regularly
Training is offered for people who get involved
People are offered payment for their time
Service users deliver training in partnership with professionals
Service users contribute to a professionally led training session
Service users are part of professional development assessment process
Service user involvement is led by a service user in a paid role
Service has peer workers who are paid employees
Service users contribute to the production of official information
The service has an independent service user panel
The service has a regular meeting that service users can attend to get involved
Services demonstrate improved quality of life linked to involvement
Services demonstrate improved mental health outcomes linked to involvement

6.8.3 Consensus on the most effective Involvement at a strategic level

Getting involved in the future of services can be both exciting and frustrating; the opportunities for change are significant, but the timescales can be long and the processes complicated. It is not always obvious where and how decisions are taken. Service users who get involved at a strategic level tend to be those who have gained involvement experience at other levels or through their experience in other professional settings.

New services are jointly designed or co-produced by service users and professionals

Co-production has become increasingly popular in recent years. Although there remains a significant amount of scepticism, there are many well regarded examples of co-produced services that would not have happened as a result of conventional development processes.

Service users are involved in the commissioning of services

In England, the separation of commissioning services from service provision (the purchaser provider split) was designed to ensure accountability to an independent authority not directly responsible for delivering the service. Service users need to be involved in the commissioning side of this transaction to ensure that this independent accountability is influenced by service user priorities alongside other criteria.

Several service users sit on the governing body

In modern mental health services, the buck stops with the governing body. This body will depend on the corporate structure of the organisation and could be directors, governors or trustees. The importance of more than one service user sitting on any governance body was emphasised by a number of people's comments – avoiding tokenism being a significant priority for involvement on the governing body to be deemed effective.

Service developments are clearly influenced by user focussed monitoring

User Focused Monitoring (UFM) offers a systematic approach to service user reviews of services; using the findings of UFM to improve future services reinforces the importance of feedback loops and helps to support the assessment of the impact of service user involvement.

Two other items received high level of support but fell short of consensus: *service user involvement is explicitly included as part of clinical governance* and *service users define the purpose and direction of the service*. Not everyone was familiar with the concept of clinical governance and a number of

people ranked it low for that reason. Others, including some who had been involved either considered that it required specialist skills to do properly or that professionals took the view that service users were no up to the task and therefore did not take their involvement seriously. Although some panel members very strongly of the view that service users should define the purpose and direction of the service, most felt that a co-produced approach was either preferable or more realistic. Table 6.5, below, summarises the individual level indicators on which consensus was reached.

Table 6.5 – Strategic level

New services are jointly designed or co-produced by service users and professionals
Service users are involved in the commissioning of services
Several service users sit on the governing body
Service developments are clearly influenced by user focussed monitoring

6.9 CONCLUSION

This research has set out to establish whether it is possible to objectively identify effective service user involvement in mental health services. This chapter has discussed the background to, and results of, my attempt to reach consensus on what effective involvement would look like. This should enable services and those that commission, deliver and receive them can improve the impact of involvement. I have found that there are many examples of service user involvement and have identified a range of characteristics that may make them effective. I have drawn on the expertise and experience of mental health service users to reach consensus on what really matters. This has led to 21 indicators of effective mental health service user involvement; these are reproduced in full in table 6.6, below.

Table 6.6 – The final indicators

Level	Indicator
Individual	People using services identify their own needs
	People have a choice of services/treatments
	The service/treatment goals are jointly set by professionals and service users
	The service/treatment focuses on the service user's strengths and potential
Operational	People involved are supported meet together regularly
	Training is offered for people who get involved
	People are offered payment for their time
	Service users deliver training in partnership with professionals
	Service users contribute to a professionally led training session
	Service users are part of professional development assessment process
	Service user involvement is led by a service user in a paid role
	Service has peer workers who are paid employees
	Service users contribute to the production of official information
	The service has an independent service user panel
	The service has a regular meeting that service users can attend to get involved
	Services demonstrate improved quality of life linked to involvement
	Services demonstrate improved mental health outcomes linked to involvement
Strategic	New services are jointly designed or co-produced by service users and professionals
	Service users are involved in the commissioning of services
	Several service users sit on the governing body
	Service developments are clearly influenced by user focussed monitoring

7 CONCLUSION AND RECOMMENDATIONS

7.1 INTRODUCTION

I have now identified 21 indicators of effective involvement using a process that draws on current practice and expert opinion applied through a rigorous process. This chapter draws some final conclusions and sets out recommendations for taking these indicators forward. There remain significant barriers to effective mental health service user involvement; this chapter suggests some of the ways in which this research can help to overcome these barriers.

7.2 IMPACT SO FAR

This research has generated considerable interest and helped to influence existing work in a range of professional settings across the mental health field. The development of indicators has contributed directly to the projects outlined below of international, national and organisational importance respectively. Even the process of creating the framework for the indicators had value. Delphi panel members, people with experience of service user involvement and many service providers and policy makers have expressed an interest in the framework and structure of the indicators. Increased awareness of the levels at which involvement can take place; a coherent (if not completely comprehensive) range of approaches to, and mechanisms for involvement; and a stronger focus on the impact of involvement have all been welcomed and prompted further discussion and developments.

7.2.1 International

The WHO has developed indicators of empowerment of mental health service users and carers. As a result of my work on developing indicators I was asked to lead a WHO working group. I also applied key learning in my role providing technical guidance to the development of the WHO Quality Rights Tool Kit (WHO, 2012).

7.2.2 National

The indicator development process contributed to the development of quality standards as part of a Welsh Government procurement process where I joined an expert working group to develop effective service user involvement in the procurement of medium and low secure services. This process has since won several awards and is being applied more widely. The use of indicators will be included in further developments of this procurement approach to a broader range of service provision.

The literature review has contributed to the National Involvement Partnership (NIP) work on involvement, influence and change and forms part of the reports from this work being led by NSUN and funded by a grant from England's Department of Health (this is still work in progress but the latest published report is attached as appendix g). The further development of this work forms part of the recommendations and next steps are outlined below.

The findings around co-production have been welcomed widely and as a result of the discussion around co-production (discussion chapter, section 6.3) the Welsh Government requested a briefing paper on the findings as they pertain to co-production to facilitate discussions on developing policy and practice around co-production. This briefing note is attached as appendix h.

7.2.3 Organisational

A small number of organisations have started to apply some of the learning from this research. The Mental Health Foundation, my own organisation, has started to become more systematic in its service user involvement and has offered this expertise to a number of partner organisations. This has included the development of involvement indicators specific to a private hospital provider and service user involvement audit work for two voluntary sector service providers. The framework has influenced the development of a number of academic research proposals and a number of statutory services in England and Wales have expressed an interest in piloting a tool based on the indicators.

7.3 FUTURE IMPACT: THE INDICATORS AS A CATALYST FOR CHANGE

A number of underpinning themes emerged from the literature, the panel comments, and the consensus process. Some are long standing issues that have been referred to in the literature over many years, and others are evolving as service user involvement evolves.

7.3.1 Rhetoric versus reality

A major recurring theme throughout this research has been the difference between what organisations (be they statutory, voluntary or private sector) say about service user involvement (at the heart of what we do, customer focussed, client centred) and how they behave (resource led, clinician led, involvement at the margins). Although this gap is repeatedly observed, it has not really been possible to quantify this gap to date and this has made focussed attempts to close this gap difficult. The use of these indicators offers a number of ways in which an organisation can improve its service user involvement in a systematic way.

1. They allow organisations to create a benchmark against which they can measure improvement.
2. They break down service user involvement into manageable components that could be dealt with in the way most appropriate to each organisation or department or function therein.
3. They can help to prioritise areas that may need particular attention.
4. They can enable different parts of an organisation to support each other to share strength and learning.
5. They can link effective involvement to service and outcome improvements and demonstrate impact.

7.3.2 Expectations matter

It is becoming more widely accepted that neither a psychiatric diagnosis nor living with mental ill-health should be barriers to a fulfilling life, but low expectations remain a significant barrier to making this a reality. These low expectations exist amongst professionals, service users and the general public and they can significantly limit people's personal development and quality of life. The use of these indicators should raise expectations, they should encourage people to think about what is possible and enable everyone involved to see the improvement over time.

7.3.3 Language matters

Although the language used is predominantly mental *health*, that is, mental *health* services and mental *health* service users, the underpinning philosophy remains mental *illness*. The medical model still dominates thinking in the mental health world. People are still assessed on the basis of diagnosis, symptoms and applying treatments rather than on the basis of need; services remain primarily deliverers of treatments rather than agents moving people towards more control of their lives. Further, focus remains on what people cannot do, people are still seen as a set of symptoms

and the goals set and performance managed around service delivery rather than making people's lives better. The indicators should help shift the emphasis from symptoms to possibilities.

7.3.4 Co-production could make a difference

Co-production is becoming more common, and good examples of co-produced services are being reported; but statutory, voluntary and private sector providers remain firmly in control of the development, delivery and evaluation of most services. As this is the nature of the allocation of resources currently available, it is not surprising that people with a great deal of experience of service user involvement should both favour working collaboratively with those who hold the resources (rather than either against them or entirely independently of them).

People remain cynical and are not expecting much to change very quickly. The language of recovery, for example, arrived with a loud fanfare and many UK services became branded as "recovery focussed" or similar and yet there is little or no evidence of any significant improvement of outcomes for mental health service users. Many people are wondering whether co-production is anything more than a similar branding exercise. Others are working hard to ensure it offers genuine improvements. These indicators will help people to establish whether any particular organisation or system has effective involvement which does lead to positive change.

7.3.5 Discrimination matters

Discrimination and stigma are frequently mentioned as concerns, blocks to progress or involvement, and are undesirable in their own right. A significant amount of time, effort and financial resources have been dedicated to challenging discrimination, and there is a reasonable evidence base for a number of approaches, particularly those based on social contact. Yet the obvious potential benefits of mental health service user involvement in this respect are not widely reported or even incorporated into many well-funded antidiscrimination initiatives. Effective involvement has the potential to challenge discrimination in a number of ways: in particular, it increases social contact between service users and others and it places service users in the role of a positive contributor rather than a passive recipient.

7.3.6 Being valued is important

The issue payment for involvement was clearly important for many of the panel members. A significant number of comments referred to the importance of payment, often in the context of people's contributions being valued, it was also considered more likely that organisations would value involvement that they had paid for. Payment also gave some people the opportunity to commit more time and effort to involvement, although it could deter some people on benefits from getting involved if payment or the possibility of payment affected benefit entitlement, leaving people worse off. The indicators around payment help to demonstrate that organisations value involvement and the people who are involved.

7.4 RECOMMENDATIONS AND NEXT STEPS

This research has led to the development of the first rigorously developed, entirely service user led, suite of indicators that are ready to use in a real world setting. In order to complete the overall goal of this work, to ensure more effective mental health service user involvement, some further work is required. The following recommendations and next steps will, if followed, embed effective involvement in the development, delivery and evaluation of the mental health services of the future.

7.4.1 Dissemination

Some elements of this research have been published, including book chapters in English and French, and technical papers for the WHO. Some part have been referenced in other work. The impact outlined above has largely come about through existing networks in some way involved either in the research or through my work at the Foundation. I have made a number of conference presentations that have included some of the methods used and emerging findings.

With the indicators now identified, I will complete further publication work and make a series of conference presentations to promote the use of the indicators.

7.4.2 Reinforcing the value of authentic co-production

The indicators have already highlighted the potential of the current interest in co-production. Further work with a specific focus on using indicators to promote authentic co-production will help to ensure that the current vogue for co-production translates into a significant change in practice and outcomes so that co-production can fulfil its potential.

7.4.3 Self-assessment tool

It is important that the indicators are easy for people to use and made readily available for both philosophical and practical reasons. I do not believe service user involvement should be owned by any organisation, but it is important that someone takes responsibility for its stewardship. A self-assessment tool would allow any organisation to benchmark and improve service user involvement in a way that works for them. Service users could, either individually or collectively, use the tool to perform basic involvement audits and use the results to support campaigns or prioritise areas for involvement.

7.4.4 Dashboards

I have previously developed an involvement dashboard to support the governance and leadership of a large service provider. A small piece of development work could easily integrate the indicators into a simple dashboard where the summary could be weighted on the basis of relative importance of each indicator to the particular setting or service users' preferences. The dashboard approach allows rapid assimilation of information with the ability to drill down for more detailed planning purposes where necessary.

7.4.5 Standards

Both self-assessment and dashboards are powerful and convenient tools for organisations or systems keen on self-improvement. A longer term goal is to offer tangible rewards to organisations that implement effective mental health service user involvement. Standards that are nationally recognised, based on valid and reliable assessment criteria have been widely used to showcase and reward excellence and progress in health and social care. They have even been used to assist commissioning and other funding mechanisms.

The development of these indicators forms part of a broader project aimed at developing national standards for service user and carer involvement in mental health services in England. NSUN has led this work and I will continue to be involved in developing the indicators into a standards framework as part of this longer term goal.

7.5 CONCLUSION

This research set out to establish a way to measure effective mental health service user involvement. To do this I have reviewed the existing literature, recruited some of the most

experienced of service user involvement experts, extracted potential indicators and exposed them to expert scrutiny. I have approached this in an open and transparent way, involving service users with expertise in involvement at every stage.

This process as led to a set of indicators that have authenticity and credibility with service users, providers and professionals alike. Their emergence also coincides and complements the current political interests in co-production. I do not think there has ever been a better opportunity to close the gap between the rhetoric and reality of mental health service user involvement and I think this research has an important part to play in this endeavour.

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9 APPENDICES

9.1 APPENDIX A - INSTRUCTIONS TO DELPHI PANEL MEMBERS

Dear All

Thank you for expressing interest in this consultation exercise. I'm delighted to let you know that you are now a member of the Delphi panel. The Panel is currently 35 people though it's possible that there may be one or two further panellists as I'm seeking a little further information from a couple of people. I would also like to receive the small number of outstanding monitoring forms and once those are in I'll let you all know a little more about the makeup of the panel; though I can already tell you that every panel member has personal experience of using mental health services and has demonstrated expertise in service user involvement.

As you've all seen a fair bit of information about the project, I'll concentrate on what comes next, and what I'm asking you to do. The purpose of Delphi panels is to reach consensus amongst expert. It's an unusual approach in that there are no physical meetings and that it involves a degree of repetition. If you do want any more information, just drop me an email.

The process in brief:

- This particular panel will be run online.
- There will be at least two rounds of questions and each round will be open for about two weeks.
- The first round should open shortly.
- You will receive an invite from the following email address Delphi Decision Aid <delphi@armstrong.wharton.upenn.edu> with a link to the questions.
- You can submit your answers to each round at any time during that two week period.
- I'll then analyse the results and prepare the next round.
- The second round should be available after a further week or so.

Now the detailed bit:

- The purpose is to help us understand what people think represents minimal, good and excellent service user involvement.
- In order to do this you will be given a number of descriptions of how organisations or services involve service users. All these statements are based on what actual organisations or services are doing as part of their service user involvement. This information has been found through a review of published literature on involvement (for those of an academic persuasion, I've included the references).
- You will be asked to put these statements in order of how effective an example of service user involvement the service in the statement is. I've given some examples below.
- There are no right or wrong answers; it's your opinion that matters.
- All responses are anonymous, although it's technically possible for me to work out who has said what, nobody else can. I will be working from anonymised data and will only look at individual responses if there are data difficulties.
- Where there is a high level of agreement (consensus), I'll report this and in subsequent rounds the questions will focus on areas without consensus.

- If you have examples of effective involvement that are not included, please let me know by the end of the first round and I'll include them in the second round.

An example:
The following statements describe how service may seek to involve service users:

a. Service involves people through a regular monthly meeting.
b. Service issues a monthly questionnaire to seek service users' views.
c. Service has a suggestion box in the main reception area.
d. Service has a telephone line where people can leave a message.
e. Service has a Facebook page where people can comment.

If you think that a Facebook page (e) is the most effective way to involve people, a suggestion box(c) is next, then a monthly meeting (a) , then a telephone line (d) and finally a questionnaire(b) you would rank as follows:

a. 3
b. 5
c. 2
d. 4
e. 1

The form will not let you rank two items the same; you have to express some preference. Remember there's no right or wrong answer, I just want your expert opinion about how effective different approaches are.

There are just over 60 statements; they are grouped in levels of involvement (individual, operational and strategic) and there are some sub groupings as well. I've attached a full list of the statements along with some references; you may find it useful to have those in front of you when you do the ranking. I'm also going to ask about where in the country you've been involved as I forgot to include this on the monitoring form and I'd like to see the geographic spread.

I've tested the web pages for Internet Explorer and Chrome on PC, it should work on most browsers on Linux or Mac, but I have tried it. I have no idea whether it will work on tablets or phones but you're welcome to try; but I cannot offer any technical support.

NSUN are handling the payment side of things, I'll send those details through shortly, it's £20 for each round completed and there will be at least two rounds.

If you have any questions, please let me know, email is almost always the quickest way to get hold of me. Thanks to all of you for your work so far and yet to come.

Best

David

9.2 APPENDIX B – INVOLVEMENT EXAMPLES, ROUND 1

Service user involvement in mental health services

Levels of involvement

I have adopted three levels of involvement: individual, people being actively involved in their own care; operational, people being involved in the services they use; and strategic, people being involved in what future services may look like. The use of these levels is widely acknowledged (see, for example, Perkins and Goddard, 2004) and helps to make the task of ranking characteristics more manageable.

All of the following approaches to involving service users have been identified from published papers I have reviewed.

Individual

1. People using services identify their own needs (Truman and Raine, 2002)
2. The service/treatment goals are set by service users (Hitchen et al., 2011, Linhorst et al., 2002)
3. The service/treatment goals are life orientated rather than symptom orientated (Braye and Preston-Shoot, 1993)
4. The service/treatment goals are jointly set by professionals and service users (Linhorst et al., 2002)
5. People have a choice of services/treatments (Hitchen et al., 2011, Kilian et al., 2003)
6. People have the positive and negative effects of treatments clearly explained (Kilian et al., 2003)
7. Service users are actively trained to achieve treatment goals (Finfgeld, 2004)
8. Professionals actively share responsibility and decision-making with service users (Tee et al., 2007, Finfgeld, 2004)
9. All discussions about services/treatments are in plain English (Connor and Wilson, 2006, Finfgeld, 2004)
10. The service/treatment focuses on the service user's strengths and potential (Stromwall and Hurdle, 2003)
11. Service user led self-help groups are promoted by the service (Segal et al., 1993)
12. People are encouraged/trained to engage in self-management (Crepaz-Keay and Cyhlarova, 2012, Lawn et al., 2007, Crepaz-Keay, 2010)
13. People are actively encouraged to find their own sources of support (Braye and Preston-Shoot, 1993)
14. Mechanisms for advanced decision-making (for example advanced directives or crisis cards) are offered (Swanson et al., 2008)

Operational

The most well developed area of service user involvement is involvement at an operational level, in the day to day running of services. This can be broken down into further categories in a variety of ways, and though this is by no means the only possible subsets, the following are suggested by the literature: training and support for involvement, staff recruitment, staff training, delivering services, service evaluation, access to resources, involvement has a measurable impact (Braithwaite, 2006, Lea, 2006, Thornicroft and Tansella, 2005, Minett, 2002, Simpson and House, 2002, Truman and Raine, 2002, Barnes and Shardlow, 1997).

Training, support and payment for service users to be involved

1. People involved are supported meet together regularly (Lea, 2006)
2. The organisation has a policy on payment for involvement (McKenna and Scott, 2007)
3. Training is offered for people who get involved (Lea, 2006)
4. People are offered payment for their time (Gregor and Smith, 2009)
5. People have their expenses paid at time of, or after the involvement (Faulkner, 2011)
6. People have their expenses paid in advance (Faulkner, 2011)

Involvement in staff recruitment and training

1. Service users deliver training independently or professionals or other trainers (Basset and Evans, 2009)
2. Service users deliver training in partnership with professionals (Benbow et al., 2011)
3. Service users contribute to a professionally led training session (Gregor and Smith, 2009)
4. Service users contribute to design the training curriculum (Higgins et al., 2011)
5. Service users contribute to the development of training (Lathlean et al., 2006)
6. Service users are part of professional development assessment process (Bailey, 2005)
7. Service users contribute to staff job descriptions (Diamond et al., 2003 suggests involvement in all parts of the recruitment process but not explicitly job descriptions)
8. Service users are involved in shortlisting candidates (Diamond et al., 2003)
9. At least one service user is part of an interview panel for all staff recruitment (Rhodes and Nyawata, 2011)

Involvement in delivering and evaluating services

1. Services provide clear information about medical treatments written by professional in clear language (Rush, 2008)
2. Service users contribute to the production of official information (Repper and Breeze, 2007)
3. Service users are provided with information written by service users (Repper and Breeze, 2007)
4. Service user involvement is led by a service user in a paid role (Middleton et al., 2004)
5. Peer support is part of the service but led by professionals (Franke et al., 2010)
6. Service has peer workers who are paid employees (Repper and Carter, 2011)
7. Service users choose their peer support (Faulkner and Kalathil, 2012)
8. The service addresses the physical health needs of service users (Cook et al., 2009, Bates et al., 2008)
9. User focussed monitoring is in place (Kotecha, 2003)

Mechanisms for involvement

1. The service has a regular meeting that service users can attend to get involved (Bowl, 1996)
2. Decision-makers from services visit service users at service user led meetings (Bowl, 1996)
3. The service has an independent service user panel (Perreault et al., 2010)
4. Some of the service's operational meetings include one or two service users (Bowl, 1996)
5. Games based approaches to involvement are used (Fitzgerald et al., 2011)
6. Meetings are structured to ensure equality of involvement for all participants (Perry and Linsley, 2006)
7. Online, social networks and other remote techniques are offered to enable involvement without physical presence (Perry and Gilbody, 2009, Langlands et al., 2008)
8. Story-telling and drama presented by service users is used as a way to present service user views (Barnes et al., 2006)
9. Service users engage in outreach work to ascertain views of other service users and report back (Rutter et al., 2004)

Measurable impact

1. Services demonstrate improved mental health outcomes linked to involvement (Crepaz-Keay, 2006, Bowl, 1996)
2. Services demonstrate improved health outcomes linked to involvement (Simpson and House, 2002, Bowl, 1996)
3. Services demonstrate improved quality of life linked to involvement (Thornicroft and Tansella, 2005)
4. Services demonstrate reduced discrimination linked to involvement (Thornicroft, 2006)
5. Barriers to involvement are identified and reported (Happell, 2008)
6. Barriers to involvement are identified and overcome (Happell, 2008)

Strategic

1. Service users attend the governing body (Crawford, 2002)
2. Several service users sit on the governing body (Grant, 2007)
3. Service users review and report to the governing body (Rutter et al., 2004)
4. Service developments are clearly influenced by user focussed monitoring (Kotecha, 2003)
5. Service users define the purpose and direction of the service (Rummery, 2009)
6. New services are jointly designed or co-produced by service users and professionals (Fitzgerald et al., 2011)
7. Services demonstrate any changes linked to involvement (Crepaz-Keay, 2006, Simpson and House, 2002, Bowl, 1996)
8. Service users are involved in the commissioning of services (Forrest, 2005)
9. Service users are involved in contract specification (Rutter et al., 2004)
10. Service user involvement is explicitly included as part of clinical governance (Stanton, 2006, Pickard et al., 2002)
11. Service users are given the resources required to develop their own services (Bowl, 1996)

And finally…

If you have any examples of your own, please let me know.

9.3 APPENDIX C – NOTE TO DELPHI PANEL MEMBERS FOR ROUND 2

Dear All

Thank you for all your contributions to round one of the Delphi process. I'm just completing the analysis and round two will start shortly, hopefully today but by tomorrow at the latest, you will receive the link once this is ready. The link will also allow you to see (anonymised) comments from other panel members.

Round two will be very similar to round one with the following differences:

- Answers where there was strong agreement amongst panel members have been removed, so there will be fewer items to rank. This should allow us to reach greater agreement.
- Some new answers were suggested by panel members, these have been added to the appropriate sections.

I've attached the updated list of questions and answers, it may be helpful to print these out and keep them with you for reference when you complete round two.

Thanks for your continued support.

Best

David

9.4 APPENDIX D – INVOLVEMENT EXAMPLES FOR DELPHI PANEL ROUND 2

Service user involvement in mental health services

Levels of involvement

I have adopted three levels of involvement: individual, people being actively involved in their own care; operational, people being involved in the services they use; and strategic, people being involved in what future services may look like. The use of these levels is widely acknowledged (see, for example, Perkins and Goddard, 2004) and helps to make the task of ranking characteristics more manageable.

Most of the following approaches to involving service users have been identified from published papers I have reviewed, except those highlighted in yellow, which were suggested by panel members. A number have been removed since round one where the average rank was particularly high or low in the first round.

Individual

1. The service/treatment goals are set by service users (Hitchen et al., 2011, Linhorst et al., 2002)
2. The service/treatment goals are life orientated rather than symptom orientated (Braye and Preston-Shoot, 1993)
3. The service/treatment goals are jointly set by professionals and service users (Linhorst et al., 2002)
4. People have the positive and negative effects of treatments clearly explained (Kilian et al., 2003)
5. Professionals actively share responsibility and decision-making with service users (Tee et al., 2007, Finfgeld, 2004)
6. The service/treatment focuses on the service user's strengths and potential (Stromwall and Hurdle, 2003)
7. Service user led self-help groups are promoted by the service (Segal et al., 1993)
8. Mechanisms for advanced decision-making (for example advanced directives or crisis cards) are offered (Swanson et al., 2008)
9. People develop their own discharge plans (suggested by panel member)
10. People contribute to their discharge plans (suggested by panel member)
11. Services have an easily accessible complaints procedure, with results collated and reported

Operational

The most well developed area of service user involvement is involvement at an operational level, in the day to day running of services. This can be broken down into further categories in a variety of ways, and though this is by no means the only possible subsets, the following are suggested by the literature: training and support for involvement, staff recruitment, staff training, delivering services, service evaluation, access to resources, involvement has a measurable impact (Braithwaite, 2006, Lea, 2006, Thornicroft and Tansella, 2005, Minett, 2002, Simpson and House, 2002, Truman and Raine, 2002, Barnes and Shardlow, 1997).

Training, support and payment for service users to be involved

1. The organisation has a policy on payment for involvement (McKenna and Scott, 2007)
2. Training is offered for people who get involved (Lea, 2006)
3. People are offered payment for their time (Gregor and Smith, 2009)

Involvement in staff recruitment and training

1. Service users contribute to a professionally led training session (Gregor and Smith, 2009)
2. Service users contribute to design the training curriculum (Higgins et al., 2011)
3. Service users contribute to the development of training (Lathlean et al., 2006)
4. Service users are part of professional development assessment process (Bailey, 2005)
5. At least one service user is part of an interview panel for all staff recruitment (Rhodes and Nyawata, 2011)

Involvement in delivering and evaluating services

1. Services provide clear information about medical treatments written by professional in clear language (Rush, 2008)
2. Service users contribute to the production of official information (Repper and Breeze, 2007)
3. Service users are provided with information written by service users (Repper and Breeze, 2007)
4.
5. Service users choose their peer support (Faulkner and Kalathil, 2012)
6. The service addresses the physical health needs of service users (Cook et al., 2009, Bates et al., 2008)
7. User focussed monitoring is in place (Kotecha, 2003)
8. Service users act as peer reviewers (suggested by panel member)

Mechanisms for involvement

1. The service has a regular meeting that service users can attend to get involved (Bowl, 1996)
2. Decision-makers from services visit service users at service user led meetings (Bowl, 1996)
3. Meetings are structured to ensure equality of involvement for all participants (Perry and Linsley, 2006)
4. Online, social networks and other remote techniques are offered to enable involvement without physical presence (Perry and Gilbody, 2009, Langlands et al., 2008)
5. Story-telling and drama presented by service users is used as a way to present service user views (Barnes et al., 2006)
6. Service users engage in outreach work to ascertain views of other service users and report back (Rutter et al., 2004)
7. Involvement mechanisms are routinely provided in accessible formats (for example: braille, large print, audio, signer for events) (suggested by panel member)
8. Involvement mechanisms always offer alternatives to online mechanisms (suggested by panel member)
9. All websites conform to W3C accessibility standards (suggested by panel)

Measurable impact

1. Services demonstrate improved mental health outcomes linked to involvement (Crepaz-Keay, 2006, Bowl, 1996)
2. Services demonstrate improved health outcomes linked to involvement (Simpson and House, 2002, Bowl, 1996)
3. Services demonstrate reduced discrimination linked to involvement (Thornicroft, 2006)
4. Barriers to involvement are identified and overcome (Happell, 2008)

Strategic

1. Several service users sit on the governing body (Grant, 2007)
2. Service developments are clearly influenced by user focussed monitoring (Kotecha, 2003)
3. Service users define the purpose and direction of the service (Rummery, 2009)
4. Service users are involved in contract specification (Rutter et al., 2004)
5. Service users contribute to evaluating service tenders (suggested by panel)
6. Service user involvement is explicitly included as part of clinical governance (Stanton, 2006, Pickard et al., 2002)
7. Service users are given the resources required to develop their own services (Bowl, 1996)

9.5 APPENDIX E – DELPHI PANEL MEMBER PERSON SPECIFICATION

Mental health service users with expertise in involvement sought

I am looking for approximately 20 people to take part in a consultation exercise to help develop indicators of effective involvement for mental health service users. People will be required to complete two or three online questionnaires at approximately monthly intervals. A small payment will be offered to those who complete the questionnaires.

Background

The National Involvement Partnership (NIP) project 'Involvement for Influence - Influencing for Improvement' aims to develop national standards for the involvement of service users and carers and establish an infrastructure for involvement. The idea is to 'hard wire' the service user and carer direct voice and experience into health and care services. The project will develop the previously evaluated NIP work, share good practice, centralise resources, strengthen existing networks and build an infrastructure that connects and coordinates involvement.

As part of this work I am consulting service user experts to seek consensus on a range of indicators to help identify how good service user involvement is in an area, service or organisation. This consultation will form part of my doctorate and inform the overall NIP project.

About the indicators

For the purposes of this work, we have taken an indicator to be a descriptor of performance against agreed values or criteria. For this work, indicators will need to relate to empowerment, as defined in the work to date. In order to develop useful and usable indicators of empowerment it is important that these indicators conform to certain characteristics; in particular, it is important that they are:

- Meaningful.
  The indicators need to measure something useful. They need to relate to core values and the definitions of empowerment that we are using. There is a risk that targets can distort practice if they are based on measuring things that do not have sufficient meaning.

- Measurable.
  To be useful, it must be possible to measure something. This measurement can take a variety of forms, for example it could be a numerical scale; a question with a simple yes or no answer; or a question with a response of the form always, usually, rarely, never. It should be possible for this measurement to be made easily without either excessive costs or disruption.

- Auditable.
  A good indicator needs to be able to be independently verifiable. Self-reporting is perfectly acceptable, provided that indicators can be audited so that they can be trusted.

- Objective
  Indicators need to be constructed so that they do not depend on the subjective opinion of the individual who is responsible for measuring the indicators.

- Offer a scale for benchmarking/improvement indicating action for improvement.
  An effective set of indicators will need to be calibrated so that any system can identify its relative strengths. It should also enable any system to improve, no matter how good they are. A good set of indicators should make it easy to see where decision-makers need to priorities and how they can improve.

About the process

The Delphi method has been chosen for this particular study because it has proven to be useful as a tool for helping groups of experts reach consensus on complicated issues. Delphi is an iterative process that consists of a number of rounds in which a long list of categories or options is sifted down to a much smaller group via consensus.

Typically are typically there are 2 to 3 rounds, although the number of rounds is not restricted. I have looked at the literature with a particular emphasis on using Delphi in mental health with a range of experts and the literature includes experts who may be professionals or service users or carers or other stakeholders. The advantages of Delphi approach are as follows:

It allows you to consult with people when they are not physically present in the room or not together at a single point in time. This allows people to contribute, who would not be able to contribute if they were expected to be in the same place at the same time it also enables people to contribute from a much broader geographical location.

This research will use a web-based Delphi. No physical meetings will occur; the only requirement for Delphi panellists is that they have Internet access.

What experience skills & knowledge would a panel member bring to this work?

We are looking for people whose experience, knowledge and skills would include:

1. Personal experience of using mental health services
2. A track record of involvement and influence, improvement and impact
3. Innovative ideas about involvement, influencing, improvement and impact
4. An in-depth understanding of the current involvement experiences and challenges faced by the diverse range of people with mental health problems and the family and friends who provide care and support to them
5. An ability to draw on your own experience and that of others who use services and/or their family and friends to inform involvement policy and service development
6. Experience of working on a formal committee at local or national level, e.g. LINKS, NHS Trust Board, Service user/carer group, School Governors, Private sector business, charity, community, cultural or faith groups
7. Experience of working with organisations at a local or national level and an understanding of how involvement could be developed strategically
8. An interest in extending the philosophy of process, presence, purpose and impact (PPPI) in service user involvement.

If you are interested, please send a brief expression of interest in a form of your choosing along with the attached form (which will help us to appoint a diverse group of people) to dcrepaz-keay@mentalhealth.org.uk . A small fee will be payable on completion of the first two rounds of the study.

9.6 APPENDIX F – DIVERSITY MONITORING FORM

Demographics

Age (Please tick one box only)
18-25 ☐ 26-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 66-75 ☐
Over 75 ☐

Gender (Please tick the appropriate box.) Male ☐ Female ☐
Transgender ☐

Ethnicity (Please put a tick one box only. If you tick "other", please write your ethnic background on the line next to the tick box.)

White		**Black British**	
British	☐	African	☐
Irish	☐	African Caribbean	☐
Other…….	☐	Other…….	☐

Asian/Asian British		**Mixed heritage**	
Bangladeshi	☐	White and African	☐
Indian	☐	White and African Caribbean	☐
Pakistani	☐	White and Asian	☐
Other…….	☐	Other…….	☐

Chinese		**Gypsy/Traveller**	
Chinese British	☐	Irish traveller	☐
Other Chinese	☐	Gypsy	☐
		Romany	☐

Other ethnic background

……. ☐

Sexual orientation (Please tick one box only.)

Heterosexual ☐ Gay ☐ Lesbian ☐ Bisexual ☐
Other.....☐

Do you consider yourself to have a disability? Yes ☐ No ☐

9.7 APPENDIX G – NSUN NATIONAL INVOLVEMENT STANDARDS 4PI REPORT

Executive summary

The National Survivor User network (NSUN) hosts the National Involvement Partnership (NIP) project. The project aims to develop national standards for the involvement of service users and carers in mental health and social care services, and establish a national infrastructure for involvement. The aim is to 'hard wire' the service user and carer voice and experience into the planning, delivery and evaluation of health and care services.
The project aims to share good practice, centralise resources, strengthen existing networks and build an infrastructure that connects and coordinates involvement. This project will promote user and carer leadership, realising the vision 'nothing about us without us'.

The National Involvement Partnership is led by NSUN and includes the organisations: Afiya Trust, Social Perspectives Network (SPN) and the Mental Health Foundation. This three year programme of work is funded by the Department of Health, and aims to bring together all of the knowledge and expertise about service user and carer involvement, built up over the last few decades, in one place.

This is a summary of the main report: The National Involvement Partnership 4PI National Involvement Standards (NSUN, 2013).

network
nsun for mental health

National involvement Partnership

The NiP 4PI National Involvement Standards

This is a summary of the main report: The National Involvement Partnership 4PI National Involvement Standards (NSUN, 2013).

Our Vision
Our vision is of a future where there is 'nothing about us without us': where effective and meaningful involvement in all aspects of our lives builds resilience and changes people's lives; where there is genuine partnership working between mental health services, professionals, service users and carers, based on agreed and shared outcomes; and where this partnership of expertise works towards common goals of respect, recovery, choice and control for each and every individual who comes to use mental health services.

Why Involvement?
The evidence tells us that good involvement can transform people's lives, improve services and develop the resilience of communities.

- Involvement in individual care and treatment can increase self-esteem, improve individual outcomes and increase people's satisfaction with services. The greatest benefits result when people agree with the purpose of their treatment, and when they have choice and control over it.
- Involvement in communities can build resilience, provide opportunities for peer support and mentoring and increase our social capital.
- Involvement in services can lead to enhanced quality of care, improved quality of life, a reduction in compulsory admissions, improved relationships between staff and service users, and improved outcomes for service users; it can also lead to improved outcomes for providers.
- Involvement in planning, commissioning and governance can improve information and access for service users, and have positive effects on decision-making processes and staff attitudes and behaviour. It is vital that service users are involved in defining the outcomes of services for these benefits to be maximised.

The 4PI National Standards:
Our work has led to the development of the 4PI framework for involvement: a simple, yet robust framework around which to base standards for good practice, and to measure, monitor and evaluate involvement.

- **Principles**
- **Purpose**
- **Presence**
- **Process**
- **Impact**

Principles

'The key point is respect and equality in working relationships... the service user is on the same level as staff, otherwise [involvement] doesn't work' (Participant in NIP Consultations)

Meaningful and inclusive involvement starts with a commitment to shared principles and values. Our work suggests that involvement needs to begin with the following shared principles and values:

- To bear in mind at all times that our ultimate goal is to improve services and to improve the mental health, wellbeing and recovery of individuals;
- The need to embrace inclusivity, equality of opportunity and fairness;
- A commitment to listen to service users and carers with respect and openness;
- A commitment to change in response to the views of service users and carers;
- Clarity and transparency from the start in all communications;
- Acknowledgement of the power differentials that exist between professionals and service users, and a commitment to minimise them where possible;
- A commitment to support race equality and to challenge discriminatory organisational practices;
- An open-minded approach towards cultural differences and diversity in ways of working;
- Sensitivity about language and actions: to acknowledge that there are different ways of expressing and doing things.

Purpose

'So it is important to clarify the purpose of involvement, how much influence a person has in the process, and how much capacity and will there is within the ▶

organisation to bring about change as a result of the involvement.' [Kalathil, 2008/2011]

The purpose of involvement needs to be both clear and shared with all of the people who are engaged in the involvement activity. The core purpose of any involvement activity should be to improve services and the experience of services for service users and carers.

- The purpose of involvement needs to be clearly stated and agreed at the start, so that everyone connected with the involvement activity or organisation knows why service users and carers are being involved;
- Clarity about the purpose of involvement should be extended to individual roles and potential activities for service users and carers;
- Clarity and transparency needs to be shared about the potential for involvement and influencing, as well as the limits of influence;
- The intended outcomes for involvement should be agreed and recorded at the start in order that they can be monitored and evaluated.

Presence

'I think they ought to be involved at the highest level. I don't know if service users and carers are being encouraged to get involved at board level. But that's what I'd like to see… We can all be involved at all levels and that would really make it work, I think.' [service user quoted in the Values-based Commissioning report]

- A diversity of service users and carers should be involved at all levels and stages of an activity, organisation or project .
- Service users and carers should be involved at all levels within the organisation, project or activity including at decision-making levels;
- Service users and carers involved in an activity should include people from diverse backgrounds and communities. This is particularly significant for communities who are over-represented within mental health services as a whole.
- At an early stage, an analysis of the population under consideration should be undertaken in order to ensure that the involvement activity reflects that population – and to ensure that people particularly affected by the service or issues under consideration are actively approached for inclusion.
- There are monitoring procedures in place to monitor the presence of service users and carers, and the diversity of those involved, throughout these levels.
- Potential roles for service users and carers within organisations were identified in the previous NIP work (this is not an exhaustive list; other roles are also possible):
  - Ambassador (i.e. committed to the ethos of the work stream or programme, promoting it, spreading the word, engaging others)
  - 'Critical friend' (i.e. both programme and involved users/ carers able and prepared to engage in meaningful debate to reach a satisfactory negotiation of work programme/policy/delivery)
  - Co-worker (i.e. working directly with programme members to deliver the work of the programme)
  - Consultant
  - Expert by experience
- Care should be taken to ensure that service users and carers can be involved separately or give their views in separate ways as their views and priorities are likely to be different.
- There should be a minimum of two and ideally three service users/carers in any meeting, with a reserve person at high level meetings; one service user or carer should never be expected to attend a meeting and represent the views of service users or carers.

Process

"We need to be involved at the very beginning, with the development of the service rather than just delivery" (Participant in the NIP Consultations)

The involvement process needs to be carefully planned and thought through, in order to ensure that service users and carers can make the best possible contribution. We have grouped the issues covered by Process under the following headings: engagement, communication, support and training, and practical issues.

Engagement:

- Information should be made widely available through a number of channels to ensure that service users and carers are informed of the opportunities for involvement;
- A range of different ways of being involved should be made

available, in order to attract a wide range of service users and carers; this may mean adopting non-traditional approaches such as outreach or working with mediators from diverse communities;

- There should be a fair and transparent recruitment process;
- Role or job descriptions should be drawn up for involvement positions, whether they are paid or unpaid, employed or voluntary;
- Flexibility should be built in, to enable people to take advantage of different opportunities and to move in and out of involvement when they wish to or need to;
- Meetings should take account of those involved and should consider reasonable adjustments, such as not starting too early in the day in response to the difficulties experienced by some people taking psychotropic medication.

Communication:

- Clear and regular communications should be adopted throughout an involvement activity;
- Jargon should be avoided – or clear and repeated explanations of terms and acronyms used should be given;
- Any written documents need to be sent out well in advance of meetings for people to have time to prepare;
- Feedback about the results or outcomes of an involvement activity should be given;
- Decision-making processes need to be open and accessible.

Support and training

If people don't have the support they feel they need, they may not feel comfortable to express themselves or [may be] overwhelmed, then it is really quite pointless" (Participant in the NIP Consultations)

- Support for those involved needs to consider:
  - Administrative support,
  - Supervision, and
  - Emotional support
- Opportunities for peer support or peer mentoring should be encouraged;
- Training should be given to enable equitable involvement and skills development;
- Training should be given to professionals/members of staff to raise awareness about involvement.
- Where possible, training should be shared by and with service users, carers and professionals taking part in an involvement process, as this can help to build a sense of team work.

Practical issues

- The policy, process and budget for the payment of fees and expenses needs to be clarified in advance of involvement;
- Information about payment of fees and 'out of pocket' expenses should be clear from the start; actual payment should be clear and timely;
- Childcare, carer and personal assistant costs should be taken into account when considering payment for people to become involved;
- Travel to be booked in advance where possible to avoid people being out of pocket.

Impact

"The end result should have outcomes or else what is the point? - and we should be informed of these outcomes". (Participant in the NIP Consultations)

We are not interested in involvement for its own sake; for involvement to be meaningful, it must make a difference. It should lead to the improvement of services and the mental health and wellbeing of service users and carers. Becoming involved can also have a positive impact on the people who are involved (for example, by giving them the opportunity for increased skills and confidence). The purpose of involvement should always remain at the centre of any attempt to assess impact.

In order to assess the impact of involvement, the following questions need to be asked:

1. What were the intended outcomes of the involvement activity? (refers back to the purpose of involvement)
2. What actual difference(s) have service users and carers made to the project, activity or organisation? (This can be monitored by continuous recording throughout a project as well as assessment at the end)
3. How did everyone feel about the process of involvement? (e.g. using 'end of involvement' questionnaires)
4. Did the involvement of service users and carers make a difference to the end result of the activity/project?
5. Did the involvement of service users and carers make a difference beyond the activity itself – to the delivery of services

or the understanding of mental health, to the recovery or wellbeing of individuals?

Impact needs to be explored in the following areas:

(further detail is given in the full report)

- Ethos/culture
- Policy and Planning
- Delivery
- Outcomes and outputs
- Diversity and equality of opportunity
- The service user and carer experience of the service

We recommend taking a cyclical approach to assessing impact: involvement should be regarded as a continuous process and follow a cycle of improvement or development: Act – Evaluate – Reflect – Learn – Act cycle. Some people may use the terminology Plan – Do – Study – Act (PDSA) used in health improvement technologies.

Where involvement happens

In order to explore further the evidence for service user and carer involvement in mental health services, we have explored involvement in the following areas, including a section on monitoring and evaluation which is relevant to all:

A: Individual care and treatment

B: Community involvement

C: Operational (services, projects, training and education)

D: Strategic (commissioning, policy, service development)

E: Monitoring and evaluation

In the full report, we summarise the research evidence for the benefits of involvement in each of these areas, the evidence for good practice and give a summary of the guidelines and tools available for supporting involvement at each level. In order to assess the impact of involvement, service users and carers should be involved throughout the monitoring and evaluation process, from setting the goals through to analysis and interpretation of the impacts identified. In the full report we recommend ways of doing this and a number of tools that can assist.

This is a working document and a developing programme of work. We plan to add to our resources over the coming months: if you know of any useful tools, measures, guidance or guidelines to aid people in achieving good practice in involvement, please do let us know. [contact details]

"I was really sceptical about being involved but have been surprised at how, if we are smart, how we can use involvement, we can really influence things.' [Service user quoted in the consultation report 'Voices of Influence' – Raza Griffiths, 2013]

Our work

The full report on the 4PI National Involvement Standards brings together the lessons and messages from the following sources of knowledge and evidence:

1. **Voices of Influence: Sounding out involvement – Raza Griffiths, 2013.** Report of consultations carried out during 2012; the NIP team consulted with 114 service users and carers at 10 consultations around England to inform the development of the involvement standards. Over 50% of participants were from BME. [LINK]

2. **NIP Literature Review of Resources – Alison Faulkner, 2012.** This review was undertaken in order to scope the standards, measures, tools and guidelines for assessing or monitoring user and/or carer involvement. [LINK]

3. **Literature Review on Involvement – David Crepaz-Keay, 2013.** This literature review aimed to source evidence based characteristics of effective service user involvement that could be refined into indicators of effective involvement. In combination with the Review of Resources (above), the aim was to ensure that what we propose in the involvement standards is based on solid evidence. [LINK]

4. **Dancing to Our Own Tunes: Reassessing black and minority ethnic mental health service user involvement – Jayasree Kalathil, 2008; reprint 2011.** The original report, published in 2008, is the report of a consultation to explore the barriers to and solutions for meaningful participation of service users and survivors from black and minority ethnic (BME) backgrounds in mental health user involvement initiatives. The review in 2011 sought to assess progress and to look at the current status of black and minority ethnic user involvement in mental health. [LINK]

5. **A review of values-based commissioning in mental health – Emma Perry, Jo Barber and Elizabeth England, 2013.** This is a review of values-based commissioning in the West Midlands. It reports an evaluation of the West Midlands mental health commissioning modelling group and consultations with service users and carers.

6. **Advice and feedback from the NIP Advisory Group and the Management Group of partners.**

7. **Report of a questionnaire consultation with service users and carers – NSUN, 2013.** [LINK]

8. **Unlocking Service User Involvement in Forensic Settings – NSUN/WISH, 2011.** Research into the provision of service user involvement in secure settings. [LINK]

9. **On Our Own Terms: Users and survivors of mental health services working together for support and change – Jan Wallcraft with Jim Read and Angela Sweeney, 2003.** London: Centre for Mental Health.

10. **The Making A Real Difference resources** – produced under NIMHE/CSIP. All are now located on the NSUN network website. www.nsun.org.uk

together we are stronger

9.8 APPENDIX H – CO-PRODUCTION BRIEFING NOTE FOR WELSH GOVERNMENT

CO-PRODUCED? Indicators of effective co-production in mental health services

INTRODUCTION

There is increasing interest in coproduction. This paper provides a brief summary of a major piece of research into effective mental health service user involvement which concluded that co-production has significant potential benefit and outlines some key indicators of effective involvement that could be used to ensure co-production offers authentic involvement.

SERVICE USER INVOLVEMENT, LEADERSHIP AND CO-PRODUCTION

There is an interesting distinction emerging between three concepts that until recently have been considered together under service user involvement as an umbrella term: co-production, service user led and peer led. The differences occur around the roles service users and professional play and the range of experiences that service users bring.

- Co-production involves both professionals and service users bringing their skills and experience to a joint process that creates something new.
- Service user led means that people who have direct experience of service use are in control.
- Peer-led implies that there is a common experience that is more than simply having used services, for example a shared diagnosis, a shared ethnic background or experience of a particular service; this distinction is relatively new (though the concept of peer support is firmly grounded in self-help movements that precede most service user involvement) and may continue to develop.

PROCESS

The aim of the research was to improve the effectiveness of mental health service user involvement in mental health services. It used the following approach: identify potential indicators of effective mental health services user involvement from existing research; recruit a team of service users with expertise in involvement; facilitate a process by which the experts agree indicators of effective involvement; support the use of the indicators as a way to improve effective involvement.

Over 200 published papers of research into service user involvement were reviewed and 64 potential indicators were drawn from these papers. In order to develop a manageable framework for indicators a three level stratification of involvement was adopted: individual, operational and strategic. The use of these levels is widely acknowledged and makes the indicators more useful and easier to analyse and act upon in a service setting.

A panel of 38 service users with considerable experience of and expertise in service user involvement were recruited. They took part in a Delphi process consisting of two rounds conducted using online Delphi software, which enabled people to take part in the process at a time, place and pace that suited them. The process was designed to seek consensus on which of the indicators presented best reflected effective mental health service user involvement.

At the end of the two rounds consensus had been reached on 21 indicators and these are reproduced in full in table 1.

CONSENSUS ON EFFECTIVE INVOLVEMENT

As consensus was reached on a number of indicators, a clear pattern emerged which favoured those that described co-production.

CO-PRODUCTION IS SEEN AS EFFECTIVE INVOLVEMENT

This occurred at each level. At the individual level "the service/treatment goals are jointly set by professionals and service users" was favoured over "the service/treatment goals are set by service users". At the operational level "service users deliver training in partnership with professionals" and "service users contribute to a professionally led training session" were favoured over "service users deliver training independently of professionals or other trainers". At the strategic level "new services are jointly designed or co-produced by service users and professionals" was favoured over "service users are given the resources required to develop their own services".

The full set of indicators of effective mental health service user involvement agreed by consensus are set out in table 1, below.

Level	Indicator
Individual	People using services identify their own needs
	People have a choice of services/treatments
	The service/treatment goals are jointly set by professionals and service users
	The service/treatment focuses on the service user's strengths and potential
Operational	People involved are supported meet together regularly
	Training is offered for people who get involved
	People are offered payment for their time
	Service users deliver training in partnership with professionals
	Service users contribute to a professionally led training session
	Service users are part of professional development assessment process
	Service user involvement is led by a service user in a paid role
	Service has peer workers who are paid employees
	Service users contribute to the production of official information
	The service has an independent service user panel
	The service has a regular meeting that service users can attend to get involved
	Services demonstrate improved quality of life linked to involvement
	Services demonstrate improved mental health outcomes linked to involvement
Strategic	**New services are jointly designed or co-produced by service users and professionals**
	Service users are involved in the commissioning of services
	Several service users sit on the governing body
	Service developments are clearly influenced by user focussed monitoring

Table 9.1 - final consensus indicators

Those highlighted in **bold** are explicitly expressed in terms of co-production, and many of the others would contribute to co-production when applied to a service setting.

POWER RELATIONSHIPS

Power relationships exist at every level of the relationship between mental health service users and those responsible for funding, developing, delivering, evaluating and regulating those services.

The starting point of the unequal relationship is need. The service user has a need and the professional is there to meet it. One party is giver and one is recipient and the power is with the giver. This power imbalance is reinforced by status and payment. The professional is paid for their part in the relationship, the service user is not. The professional is trained and supported in their role, they are part of a team, they are part of a professional body, the service user is not. The social status applied to a clinical professional is high, the social status of a psychiatric patient is not. Possibly even more significantly, for the professional the transaction is a job, they get to go home afterwards, for the service user it's their life, and they are stuck with it.

A number of the indicators above that are not directly co-productive in nature provide help to address some of these power imbalances and there create an environment in which co-production is more likely to flourish.

CONCLUSION

That co-production to be consistently favoured over service user led or peer led seems to be a product of a number of factors:

- The concept of mental health service user involvement is strongly associated with joint work rather than service user or peer led work.
- High importance was put on the relationship between service users and professionals not just the nature of the service itself.
- Working with professionals was thought to be more effective than working independently of them, both in terms of improving services and outcomes, and also as a way of challenging discrimination, through social contact for professionals with service users in positive roles.

If this reflects a wider view, then the current high profile of co-production may lead to more widespread effective service user involvement.